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DIPLOMARBEIT

Titel der Diplomarbeit

How to face a young life's end?

Coping with terminal illness in Jenny Downham's *Before I Die*.

Verfasserin

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Declaration of Authenticity

I confirm to have conceived and written this thesis in English all by myself. Quotations from other authors are clearly marked and acknowledged in the bibliographical references either in footnotes or within the text. Any ideas borrowed and / or passages paraphrased from the works of other authors are truthfully acknowledged and identified in the footnotes.

Katharina Süss

Hinweis

Diese Diplomarbeit hat nachgewiesen, dass die betreffende Kandidatin befähigt ist, wissenschaftliche Themen selbstständig sowie inhaltlich und methodisch vertretbar zu bearbeiten. Da die Korrekturen des Beurteilenden nicht eingetragen sind und das Gutachten nicht beiliegt, ist nicht erkenntlich, mit welcher Note diese Arbeit abgeschlossen wurde. Das Spektrum reicht von sehr gut bis genügend. Die Habilitierten des Instituts für Anglistik und Amerikanistik bitten, diesen Hinweis bei der Lektüre zu beachten.

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INTRODUCTION

I have for a long time been attracted to the intriguing problem that we are unable to grasp our own death, that "[i]t is inconceivable for our unconscious to imagine an actual ending of our own life [...]." (Kübler-Ross, *On Death and Dying* 2) Unfortunately, only dramatic messages shake us up and clear the way for a change in our attitude towards life that seems to be more than desirable. After all, "[i]t's only when we truly know and understand that we have a limited time on earth – and that we have no way of knowing when our time is up, we will then begin to live each day to the fullest, as if it was the only one we had." (Lundy and Janes 1089)

Tessa Scott, Jenny Downham's protagonist in *Before I Die*, received the dramatic message of a terminal illness and knows that she has only a few months left. She decides to live before she dies, feeling that this is "the only thing that makes sense." (Downham 54)

The awareness of mortality and of an approaching death does not only change the lives of the dying themselves, but also the lives of the people who know and love them. The picturing of these changes as well as of the way in which the individual characters in *Before I Die* cope with the knowledge of the young woman's terminal illness is in the centre of attention of the paper at hand. Analysing the text by an approach through close reading, the aim is to find out in which way medical and psychological phenomena are presented in the novel.

I decided to make use of the potential of an interdisciplinary approach, gaining theoretical insights from both medicine and psychology and applying them to Jenny Downham's novel. The focus will not only be laid on childhood leukaemia, but particularly also on palliative care, based on the ambitious work done by Elisabeth Kübler-Ross and David Kessler. The fact that Jenny Downham is acquainted with Kübler-Ross's five Stages of Grief and refers to them in *Before I Die* added to the appeal of focusing on this model in my paper.

The first chapter of the paper at hand is dedicated to Jenny Downham and her work. It does not only provide the reader with biographical information about the author, but also with a brief summary of the contents of *Before I Die*. Moreover, this chapter

contains an assessment of the novel's placement in the realm of literature and questions its classification as a young adult novel. Furthermore, on the basis of Franz Karl Stanzel's model, the narrative technique of the novel is to be analysed. The three elements in his narratology – person, perspective and mode – will be in the centre of attention.

Dealing with the medical and psychological background, the second chapter is divided into two subchapters. Focusing on the results of childhood cancer research in the first one, some basic information about the nature of leukaemia, the different types, frequent symptoms and possible treatment is to be given. The emphasis of the second subchapter will be on the results of research in the field of palliative care. After a brief comment on Elisabeth Kübler-Ross's life, her work of a lifetime, the five Stages of Grief, will be outlined. Similarly, David Kessler is to be introduced briefly, before I shall illustrate his study on the Needs of the Dying.

Chapter three is dedicated to the way in which the main character's disease is represented in Jenny Downham's novel. The picture drawn by the author of the development of the young woman's leukaemia and of its treatment as well as the references to the medical instruments which are used shall be investigated critically.

In the fourth chapter, the main character's way of coping with her physical pain is to be analyzed. The strategies the protagonist develops in the course of her disease and the scenes pictured by Jenny Downham in which the young woman receives help from members of her family, her friends or the medical staff are to be looked into.

On the basis of the theoretical background presented in the second chapter, chapter five focuses on the representation of the protagonist's emotional pain. The similarities between the Needs of the Dying as they are described by David Kessler and as they are presented by Jenny Downham in the case of the young protagonist are assessed.

Focusing on emotional pain, the aim of chapter six is an analysis of Kübler-Ross's five Stages of Grief and their relevance to the novel. This part is divided into two sub-chapters: The first one deals with the main character and the second one with the people who encounter her, either privately or professionally, regularly or only occasionally.

Finally, in chapter seven the effects of the knowledge of the young woman's terminal illness on her life and the life of the people close to her are to be analysed. Of interest is not only the impact of the disease on the protagonist's character, but also the development of the relationships between the main character and the members of her family, her friends, the medical staff and other people she encounters after being diagnosed acute lymphoblastic leukaemia as well as the relationships between the people who know Tessa.

1. AUTHOR AND HER WORK

1.1. Jenny Downham

1.1.1. Life[1]

Jenny Downham was born in London in 1964. After trying her luck in the film business and before starting to write, Downham worked as an actress in the improvised-theatre company *Tellers Theatre*. Touring through the country, they were putting on plays in prisons, mental hospitals and youth clubs. After having worked with them for seven years, she left the theatre company in 1999, six weeks before the birth of her second son. According to Downham, it was the improvisation of plays for a more or less reluctant audience that taught her both to create characters and to tell stories.

Downham emphasizes the necessity for her picking up the writer's pen. She "didn't know what to do with the playful energy that [she]'d been using every day as an actor. Writing began as an outlet for that."[2]

After entering the *London Writer's Competition* in 2003 and winning first prize, Downham felt encouraged to join a writer's group. By 2005 she had finished her first novel, but after meeting several agents and publishers she realized that a considerable amount of re-writing was necessary. Rather than devoting her time to editing, she decided to focus on the second novel she had in the meantime started to write on. *Before I Die* was finally completed in February 2007.

Being a single mother, Downham lives in Hackney in east London with her two sons and is currently working on a new book.

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[1] ---. "Jenny Downham." http://de.wikipedia.org/wiki/Jenny_Downham (02/17/10).
[2] Hibbert, Katherine. "No trace of corn." http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article1894252.ece (02/18/10).

1.1.2. Work[3]

According to Downham, the writing of *Before I Die* took her "two and a half years from conception to completion."[4] She did not have a clear concept from the beginning on-wards:

> I started with the voice. I didn't know Tessa was dying, she just seemed to be very sad and angry, and I wasn't sure why. After six months it became apparent. Also, when the London bombings happened [in July 2005], it struck me that so many people I knew were affected. Life becomes very concentrated and it really impacted the writing. I realized that when you put the clock ticking, in many ways you highlight the narrative drive.[5]

In the process of writing she made and still makes use of techniques she got to know while working as an actress: "I keep notebooks and journals and diaries for the characters, researching them as if I'm going to play them on stage – what they like to eat, what their hopes and fears are. It might not all get in the book, but it helps me to know who they are."[6]

In addition to the general influence of Raymond Carver's poetry on her work as a writer, Downham was mainly inspired by Susan Sontag's *Illness as Metaphor* and Anatole Broyard's *Intoxicated by My Illness*. In the course of her research Downham also read memoirs by adults with cancer and showed her manuscript to nurses at Great Ormond Street Hospital in London, specializing in young children cancer. However, Downham decided not to interview any dying children, arguing: "I felt that if I talked to an ill teenager, I would feel compelled to write their story exactly as it was for them. And I didn't want to serve just one person's story. I wanted to write a story about mortality and about growing up, which Tessa has to do in a very short space of time."[7]

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[3] Switzer, Kristen. "Author Profile: Jenny Downham." http://www.teenreads.com/authors/au-downham-jenny.asp (05/04/10).
[4] Switzer, Kristen. "Author Profile: Jenny Downham." http://www.teenreads.com/authors/au-downham-jenny.asp (05/04/10).
[5] BookBrowse.com. "Jenny Downham: Biography." http://www.bookbrowse.com/biographies/index.cfm/author_number/1486/Jenny-Downham (05/01/10).
[6] Switzer, Kristen. "Author Profile: Jenny Downham." http://www.teenreads.com/authors/au-downham-jenny.asp (05/04/10).
[7] Hibbert, Katherine. "No trace of corn." http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article1894252.ece (02/18/10).

Before I Die is Downham's first and so far only published book. After she had finished writing in February 2007 and met her agent Catherine Clarke in March 2007, her novel was published by David Fickling in July 2007. Within two weeks foreign rights were sold in several languages. Until the present day, *Before I Die* has been published in English, German, Japanese, Swedish, Italian and Dutch.[8] Both the English as well as the German version of the novel have appeared in two editions: One for young adults and one for adults.

In 2008, Downham's *Before I Die* won the *Branford Boase Award* and was listed under the *ALA Best Books for Young Adults*. It was not only short listed for the 2007 *Guardian Award* and the 2008 *Lancashire Children's Book of the Year*, but also nominated for the 2008 *Carnegie Medal* and the 2008 *Booktrust Teenage Prize*.[9]

When being asked what *Before I Die* is actually about, Downham argued that for her

> [t]he novel is about the pursuit of the list. It's about the things that she gets, the things that she doesn't, about how the list changes, but it's also about her recognition that getting what you want doesn't always give you what you need and sometimes the most unexpected things can move you in a very profound way. And it's also about her family, because the list has consequences, both for her and for the people who love her, and this is so difficult for them. How do you limit a teenager who is dying? How do you say, "You can't have this experience, its too dangerous!", when all this young person wants to do is feel, anything? And so they struggle with her list, with her physical deterioration and also with their own loss. And they do that in different measure, depending on who they are.[10]

When asked what she hoped *Before I Die* to be, she answered that she wished the book not only to be scary, but at the same time also uplifting:

> I hope it's really scary, because Tessa is only 16 and she's having to look death right in the face and that's an enormous thing to have to do. And I also hope, despite the subject matter, that it's really uplifting. I wanted to write a book that looks at what it really means to be alive. A celebration of what it means to be alive, because if life is boundaried and death is the biggest

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[8] Online Computer Library Center. "Downham, Jenny." http://worldcat.org/identities/lccn-n2007-39040 (02/17/10).
[9] ---. "Jenny Downham." http://en.wikipedia.org/wiki/Jenny_Downham (02/17/10).
[10] Meet the Author Ltd. "Jenny Downham." http://www.meettheauthor.co.uk/bookbites/1689.html (02/18/10).

> boundary of all, then the smallest, seemingly insignificant things can become rich and for somebody like Tessa, who is looking at life in a very concentrated way, because she's about to leave, she is able to pursue, with great clarity, the things that truly matter.[11]

1.2. Before I Die

1.2.1. Contents

Before I Die is narrated by sixteen-year-old Tessa Scott, who – having lived with acute lymphoblastic leukaemia for four years – gets the information that her disease is advanced, that no remission can be expected and that there are only a few months left for her to live. She decides to take her life into her own hands, stops tiring treatment and starts a list of the things she wants to do before she dies. This ever-growing and ever-changing list mirrors her altering desires and shows in an extraordinarily convincing way how her priorities change. "Released from the constraints of 'normal' life, Tessa tastes new experiences to make her feel alive while her failing body struggles to keep up."[12]

After experiencing a disappointing loss of her virginity, one day of saying "yes" to everything she is being asked to, drugs and the commitment of crime, she falls in love with her young neighbour, Adam, who has lost his father and after having moved house looks after and cares for his grieving mother. Her love for this boy makes it possible for Tessa to savour life despite uncountable hospital visits, tests and drugs and gives her the strength to spend her last months in a self-determined way.

In contrast to the people surrounding her, "Tessa herself is […] defiantly set against blind hope."[13] She faces her fate and develops strategies which help her cope with the physical and emotional pain accompanied by her disease and the knowledge of her limited amount of time. Untypical for young people of her age, she starts to feel with great intensity and to perceive environmental phenomena much more consciously. Her

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[11] Meet the Author Ltd. "Jenny Downham." http://www.meettheauthor.co.uk/bookbites/1689.html (02/18/10).
[12] BookBrowse.com. "Before I Die: Summary." http://www.bookbrowse.com/reviews/index.cfm/book_number/2031/Before-I-Die (08/09/10).
[13] Collins, Robert. "Dying for a happier ending." http://www.guardian.co.uk/books/2007/jul/15/booksforchildrenandteenagers.features2 (08/09/10).

thoughts about life and death are increasingly characterized by profundity and, therefore, evidence of her exceptional growth of maturity.

Not only does Tessa's disease and the knowledge of the temporal proximity of her death change her own life and way of living, but also the life and way of living of the people in her environment:

> There's sweet, decent, brokenhearted Dad, whose survival drug is earnest denial. There's selfish, ineffectual Mum, who left them four years earlier and still seems several steps removed from the messy playing field of emotional responsibility. "How can I feel older than my own mother?" Tessa wonders. "I close my eyes so I don't have to see her fail." There's Tessa's younger brother, Cal, who gives his sister a book called "A Hundred Weird Ways to Meet Your Maker" and says helpful things like "When Tessa dies, can we go on holiday?" There's her best friend, Zoey, a rampaging narcissist in a minidress. And there's Adam, the boy next door, recently made fatherless, who gardens and rides a motorcycle and looks after his grieving mother, yet who is not conventionally handsome, not perfect (perfection being not what Tessa's after, since it is, probably, not life).[14]

Particularly her parents find themselves in the difficult situation of having to decide where to draw the line between, on the one hand, giving justice to the special situation their daughter finds herself in and, on the other hand, to protect her from doing damage to herself and others.

The relationships between Tessa and the people caring for her, namely the members of her family, her friends and the medical staff, but also the relationships between these people, change. Generally, the relationships become closer and deeper in the precious weeks, days and hours before the young girl's death.

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[14] Schwartz, John Burnham. "What She Wants." http://www.nytimes.com/2007/10/14/books/review/Schwartz2-t.html (08/06/10).

1.2.2. Type of literature[15]

Given that Jenny Downham's *Before I Die* is and can be characterized as being "targeted at teens with crossover appeal for adults in general,"[16] it seems reasonable to argue that it is part of the genre called young adult literature.

Proposing a definition of this genre, *The Oxford Encyclopedia of Children's Literature* states the following:

> The category of young adult literature generally refers to texts addressing an audience from about thirteen upwards, including books whose themes and writing strategies suggest that their audience is at the upper end of the teenage years. In general, such texts are informed by the values and assumptions about adolescence that are dominant in the culture at the time of the texts' production, but the genre can also be loosely defined by its central concerns and interests, characteristic subject matter, narrative strategies, and genres. (*The Oxford Encyclopedia* 215)

Young adult literature can be placed between children's literature or junior fiction on the one hand and general literature or adult fiction on the other hand. It aims at preparing its readers both for the complexity and for the themes typical of adult literature.

The history of the development of the genre of young adult literature is a relatively short one. Even though Jules Verne, G. A. Henty, Robert Louis Stevenson and R. M. Ballantyne produced literature for adolescents already in the middle of the 19th century, the time in which also youth magazines and school stories came into existence, it was not before the second half of the 20th century that *The Catcher in the Rye* by J. D. Salinger was first published in 1951 and opened the era in which writing for young adults became popular.

The historical development of the young adult novel was strongly influenced by the novel of education. In contrast to this type of novel, however,

> [t]he young adult novel usually has a much shorter time span, but – as Roberta Trites has shown – in focusing on crucial formative moments in a

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[15] "Young Adult Literature." *The Oxford Encyclopedia of Children's Literature.* New York (et. al.): Oxford University Press, 2006.

[16] BookBrowse.com. "Jenny Downham: Biography." http://www.bookbrowse.com/biographies/index.cfm/author_number/1486/Jenny-Downham (05/01/10).

> character's transition from adolescence to adulthood and in conceiving of that transition as a journey or rite of passage involving processes of development and education, young adult novels incorporate elements of the bildungsroman genre. (*The Oxford Encyclopedia* 216)

In the 1960s, the so called problem novel became popular. Representatives of this genre tell the stories of characters facing personal problems as well as problems with members of the family and society in general. Moreover, "[t]hey typically deal with marginally taboo subject matter – sex, pregnancy, drug abuse, homosexuality, and so on – and usually deal with these issues in a manner that is instructive." (*The Oxford Encyclopedia* 216)

Even though *Before I Die* picks out problems of all the before mentioned three levels as a central theme and includes taboos on a frequent basis, Jenny Downham clearly does not broach these issues in an instructive way. This was her conscious decision, arguing: "I don't think my job as a writer is to moralise. If I was setting out to write a book telling young people how to behave, they wouldn't read it. I didn't want to make judgments about what Tessa decides to do, but to show that any choice has consequences."[17]

From the 1970s onward, the first so called new realist novels were written. "Like the problem novel, new realism deals with taboo subject matter, but also includes a socially critical and political dimension that is often pessimistic and cynical." (*The Oxford Encyclopedia* 216)

Even though *Before I Die* is neither socially critical, nor political in any striking way, it can nevertheless be argued that both a socially critical as well as a political element are indeed present. After all, Downham does not only portray people, even medical professionals, who cannot cope with the knowledge of a person's temporally close death and criticizes that as a consequence – often unintentionally – the terminally ill are excluded from social life. But there is also the clearly political topic of medical and financial support for cancer patients is addressed. It is through the mouth of Tessa's father that Downham seems to point towards the "[p]aucity of teen cancer units, lack of

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[17] Hibbert, Katherine. "No trace of corn." http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article1894252.ece (02/18/10).

funding for alternative medicine" (Downham 187) and the "dietary needs not being subsidized by the NHS." (Downham 187)

Apart from the two forms of realist writing, problem novels and new realist novels, fantasy writing is sometimes argued to be part of young adult fiction. Despite its popularity, however, critics tend to focus on realism and exclude fantasy literature when dealing with this genre. The reason for this is that the readership of fantasy literature is varied and cannot be narrowed down to adolescence.

As far as the understanding of adolescence is concerned, literature of Western societies seems to be influenced by two cultural schemata: The first schema sees young adulthood as the "time for rebelling against and rejecting the adult world, being non-conformist, gaining freedom and experimenting with self-images, lifestyles, and behaviors." (*The Oxford Encyclopedia* 217) The second schema sees this period as the "time for maturing, learning, and growth, becoming an adult, accepting adult responsibility and exploring the adult world." (*The Oxford Encyclopedia* 217)

Undoubtedly, both schemata can be found in *Before I Die*. After all, on the one hand, Tessa rejects large parts of her parents' world and finds herself in a struggle for self-determination as far as both her way of living and dying is concerned. On the other hand, she at the same time walks the road of maturation, increasingly realizing what it means to become an adult and to take responsibility for her words and actions.

According to *The Oxford Encyclopedia of Children's Literature*, critics claim that the topics dealt with by authors writing for young adults basically fall into three categories. The first one is personal issues. "[T]he body, appearance, sexuality, romance, pregnancy, drug abuse, [and] suicide" (*The Oxford Encyclopedia* 217) are frequently being addressed. The second one is intrafamily issues. Authors of young adult literature often pick out conflicts both between and within generations and the break-up of a family as a central theme. The third one is interpersonal issues. "[P]eer group interactions and conflicts, gendering, conflict with authority, disharmony between personal situation and contemporary culture or sociality, and alienation" (*The Oxford Encyclopedia* 217) are examples of this category.

Obviously, the primary focus in *Before I Die* is on the main character's personal issues. All of the elements belonging to this category are being addressed in one or the other

way. These are, however, by far not the only elements being addressed in the novel. Jenny Downham also features intrafamily issues. Conflicts both within and between generations do not only occur in Tessa's family, but also in her friends' families. Finally, also elements of the third category, interpersonal issues, are included.

Young adult literature increasingly being "packaged to look like adult titles," (*The Continuum Encyclopedia* 786) publishers "publishing what are clearly YA books as adult titles" (*The Continuum Encyclopedia* 786) and a rising number of young adult pieces of literature produced by established adult writers, the line between literature for adults and literature for young adults is not as clear as it used to be.

The boundaries concerning suitable topics for young adult literature have been largely eliminated within the last few decades. "The resulting product has been widely described as 'edgy' literature – literature that has the freedom to explore the often hard-edged realities of contemporary YA life in creatively risk-taking ways." (*The Continuum Encyclopedia* 786)

Dealing with, sex, drugs and crime, Jenny Downham's *Before I Die* can definitely be argued to be part of this edgy type of literature.

According to *The Oxford Encyclopedia of Children's Literature*, young adult literature is frequently characterized by a first-person narrator, the use of present tense and vernacular language. *Before I Die* is characterized by all of these three features, which clearly supports the argumentation that it is part of young adult literature. Furthermore, the following concerns are typical of young adult literature as well:

> a recognition of the selfhood of others and movement out of solipsism
> a sense of 'knowing where one is going'
> a sense of individual uniqueness
> the establishment of a separate identity
> solidarity with a group's ideals
> a recognition that the immediate future demands choices among conflicting possibilities
> a growth of cognition
> the struggle between public and private concepts of self
> the struggle between dependency and independency;
> experience of physical sexual maturity;
> consciousness of self in interaction with others;
> reevaluation of values, worldviews, belief systems;
> mature personal relationships
> confirmation of gender roles

> achieving emotional independence of parents and other adults. (*The Oxford Encyclopedia* 217)

Tessa recognizes that – just as each and everybody in her environment – she is unique, that she has the right and obligation to be herself and needs to establish a distinctive, separate identity. She is perfectly aware of the fact that in order to be able to go her own way some decisions have to be made and that she has to choose among conflicting possibilities. After all, Tessa has to decide whether or not she wants to stop taking heavy treatment which on the one hand – even if the chances are rather small – might get her closer to a cure, but on the other hand restrict her quality of life severely. Jenny Downham pictures the girl's realization that it is both her life and death and that she therefore has the right to live and die the way she wants to. Hand in hand with her making her own decisions, Tessa starts taking responsibility and showing maturity.

Also the constant struggle between dependency and independency is represented in *Before I Die*. In the course of time, at least to a certain extent, the main character seems to achieve emotional independence from her parents, realizing that she is allowed, if not even required, to make some decisions on her own.

Even if this might sound cynical, one could definitely argue that Tessa – in the course of the novel – also develops a sense of "knowing where [she] is going." After all, she becomes aware of the gravity of her disease and decides to live accordingly. She does not only re-evaluate her values, but also changes large parts of her worldviews and, generally, experiences growth of knowledge, spirit and mind.

In *Before I Die*, Jenny Downham presents the difference between mature and immature personal relationships and deals with the acceptance or neglect of responsibility as the distinctive feature. The main character's relationship as an example of a mature relationship is opposed to her friend's relationship which can clearly be characterized as an immature one.

Due to the fact that the majority of the before mentioned concerns come up in Downham's novel, *Before I Die* can clearly be classified as a typical example of young adult literature.

1.2.3. Narrative technique[18]

Stanzel distinguishes between three narrative situations, namely the first-person narrative situation, the authorial narrative situation and the figural narrative situation. It is the differing dominance of the three elements person, perspective and mode that accounts for the various types. "The mediacy of narration […] forms the basis for the distinction among the three narrative situations in such a way that in each narrative situation a different element (person, perspective, mode) of the mediacy complex is dominant." (Stanzel 5)

In the first-person narrative situation, the dominating element is person. The first-person narrator is a character in the fictional world. In the authorial narrative situation, (external) perspective is dominant. Finally, in the figural narrative situation it is mode that rules over both person and perspective. The reader is confronted with a reflector. "The narrative situations are thus constituted by the triad mode, person and perspective. Each of these constitutive elements permits of a great number of actualizations which can be represented as continua of forms between the two extreme possibilities." (Stanzel 51)

According to Stanzel, the binary opposition of the formal continua referred to are identity and non-identity of the realms of existence of the narrator and the characters for the element person, internal and external perspective for the element perspective and narrator and reflector for the element mode.

Stanzel argues that being ideal types, the actual works of literature never fully and exclusively match one of them: "It was not my intention to restrict the multiplicity of narrative possibilities to a limited number of categories by means of the typology of the narrative situations." (Stanzel 46)

1.2.3.1. Person

The first element Stanzel describes is the relationship between the narrator and the fictional characters. The narrator can live in the fictional world of the characters and is

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[18] Stanzel, Franz K. *A Theory of Narrative.* Cambridge: Cambridge University Press, 1987.

then referred to as a (personalized) first-person narrator. Alternatively, the narrator lives outside this world, which is when he or she is an (authorial) third-person narrator.

In contrast to the authorial third-person narration,

> [i]t is characteristic of the *first-person narrative situation* that the mediacy of narration belongs totally to the fictional realm of the characters of the novel: the mediator, that is, the first-person narrator, is a character of this world just as the other characters are. The world of the characters is completely identical to the world of the narrator. (Stanzel 4)

Jenny Downham's *Before I Die* is, therefore, clearly a first-person narration. After all, the narrator, Tessa, is also the protagonist and thus inevitably lives in the world of the fictional characters. According to Stanzel, this does have significant consequences on the information the reader is given: "The presence of such a narrator in the world of fictional characters and his endowment with an individuality which is also physically determined leads to a limitation of his horizon of perception and knowledge." (Stanzel 89)

Stanzel emphasizes that this lack of reliability cannot be accounted for by the personality of the character in the fictional world, but by a lack of available information.

It seems plausible to argue that one of the most striking reasons for Jenny Downham's decision to make use of first-person narration was the fact that it is, in contrast to third-person narration, a personal form of narration: "Everything that is narrated in the first-person form is somehow existentially relevant for the first-person narrator." (Stanzel 98)

Given that in a first-person narration the narrator's "corporeality is part of his existence as an experiencing subject," (Stanzel 90) it seems to have been a valuable choice by Jenny Downham to make use of this narrative form. After all, both her body and her mind are affected by Tessa's illness and nobody could express the effects better than Tessa herself. "The narrative process and the narrator's experience form an entity; in other words, the reader is constantly invited to keep in mind this existential unity of the experiencing self and the narrating self." (Stanzel 93)

The narrator and the hero of the story being one and the same person, the novel is a quasi-autobiographical first-person narrative. Tessa is the main character and heroine of

the story and it is through her consciousness that the reader is informed about the happenings.

1.2.3.2. Perspective

Stanzel's second element deals with the point of view from which the story is narrated. The two extreme poles are termed by Stanzel "internal perspective" and "external perspective":

> Internal perspective prevails when the point of view from which the narrated world is perceived or represented is located in the main character or in the centre of events. (Stanzel 111)

> External perspective prevails when the point of view from which the narrated world is perceived or represented is located outside the main character or at the periphery of events. (Stanzel 112)

The story being presented by the main character of the novel, narration in *Before I Die* clearly happens from an internal perspective. This enhances the development of a strong emotional connection between the readership and Tessa. After all, Stanzel argues that by providing insights into the consciousness of a character, the reader's sympathy can be evoked: "The more a reader learns about the innermost motives for the behaviour of a character, the more inclined he tends to feel understanding, forbearance, tolerance, and so on, in respect to the conduct of this character." (Stanzel 128)

Additionally, Stanzel points out that "[i]nternal perspective necessarily results in a restriction of the kind and degree of knowledge […]." (Stanzel 126)

This can frequently be observed in the novel. At one point, for example, Tessa is sitting on a tree after consuming psychedelic mushrooms, still under their influence, and is asked by Adam to get down from the tree cautiously. The first-person narrator obviously does not know what her friend perceives, or in this case, hears: "[T]he tree wraps its arms about me and begs me not to. I try to explain this to Adam, but I'm not sure he hears me. He's taking off his coat. He starts to climb." (Downham 100)

Generally, in the case of internal perspective, the readership is informed about the thoughts and perceptions of only one single character. In order to give the reader the possibility to draw his or her own picture of the other characters and to inform about

what they think or say about the protagonist, Jenny Downham frequently includes dialogue. Sometimes she also makes use of the device of eavesdropping. Tessa and her brother "creep down the stairs and peer over the banister," just to overhear the following conversation between their parents in which their attitude to the situation in which they find themselves becomes manifest:

> "I'm bloody knackered."
> "I can see that."
> "The boundaries change all the time. One minute she doesn't want anyone near her, then she wants to be held for hours. […]" He looks at her very intently. "I'm not sure how much more I can manage by myself. Some mornings I can hardly bear to open my eyes." (Downham 146)

In another situation, the reader seems to be informed about the way Tessa's father thinks and feels. However, one has to be aware of the fact of course that in this situation no direct access to Tessa's father's mind is granted. After all, the reader is strongly influenced by the girl's presentation and interpretation of his sigh: "I hate him. I know he watches me leave. I hear his small sigh of relief." (Downham 103)

1.2.3.3. Mode

With "mode" Stanzel refers to the relationship between the narrator or reflector and the reader. Narration, overt mediacy, can be distinguished from presentation, covert mediacy. Whereas in the case of narration the reader is confronted with a personalized narrator, he gets the impression of being directly confronted with the events happening in the case of presentation. Narration and presentation are characterized by the existence of a teller-character and a reflector-character respectively.

"There evidently exists a close correspondence between internal perspective and the mode dominated by a reflector-character, on the one hand, and between external perspective and the mode dominated by a teller-character, on the other." (Stanzel 141) This also holds true for *Before I Die*. After all, the novel is characterized by both internal perspective and the existence of a reflector-character as narrator and protagonist.

Stanzel came up with some features of a narrative characterized by the existence of a reflector: The opening which, according to Stanzel, tends to be abrupt and etic in case of the reflector-mode is of particular interest as far as this third element is concerned. In *Before I Die*, Tessa being the reflector-character, the reader is confronted with the

experiencing self from the very first sentence onwards: “I wish I had a boyfriend. I wish he lived in the wardrobe on a coat hanger.” (Downham 1)

Whereas, according to Stanzel, “an ‘I’ appearance at the beginning of a narrative always refers to the agent of transmission,” (Stanzel 159) namely a teller-character, “[t]he ‘I’ at the beginning of an interior or silent monologue is a special case, and does not function as a teller-character, but rather as a reflector-character.” (Stanzel 159)

This has an interesting effect on the reader: “In the case of a narrative beginning with a reflector-character, the reader is obliged to forgo all preliminaries and to place himself in the position of the reflector-character, experiencing the narrated event in actu.” (Stanzel 160)

Furthermore, Stanzel argues that, in contrast to the teller-character, the reflector-character is not aware of his or her role as a narrator. There is a “[t]endency toward concrete particularity, toward impressionism and empathy.” (Stanzel 169) “The reader seems to find out directly, by direct insight into the consciousness of the reflector-character, about the events and reactions which are mirrored in this consciousness.” (Stanzel 144)

The events are of immediate importance for the reflector-character and presented as they occur, which is indicated by the temporal deictic expression “now” and the special deictic expression “here”. According to Stanzel, the reflector grants the reader insights into a certain part of the fictional reality, which, in contrast to information conveyed by a narrator, are detailed and impressionistic: “In the presentation by a reflector-character individual and concrete details which have not been reduced or abstracted dominate, just as they are experienced and perceived by that character.” (Stanzel 153)

Obviously, this leaves the readership in the dark as far as all details are concerned that cannot be grasped by the reflector: “Outside of this sector, however, there is darkness and uncertainty, a large area of indeterminacy, which the reader can penetrate only here and there by drawing inferences from the illuminated sector.” (Stanzel 153)

In contrast to a narrator, a reflector does not address the reader in any way, “[…] does not have any personal relationship whatsoever with the reader, and therefore is not

accountable in any way for what is recorded by his consciousness and what is not perceived." (Stanzel 154)

Neither is the reader addressed by Tessa, nor does she refer to what is being or has been narrated. The only deviation from the reflector-mode is the inclusion of Tessa's letters to the members of her family and her friends in which she gives them "instructions" for the time after her death.

Generally, the reader is informed through her thoughts and states of consciousness. It provides a mirror of the things she perceives, thinks and feels. It is the experiencing self that clearly dominates over the narrating self: "The more the narrating self of a first-person character withdraws, exposing the experiencing self directly, the closer this first-person character moves to the function of a reflector-character." (Stanzel 149)

1.2.3.4. Further narratological features of *Before I Die*

The entire novel is characterized by large parts of narrated monologue. Additionally, the reader is confronted with dialogues, both between the narrator and other characters and exclusively between other characters.

Of particular interest are the before mentioned included instructions. These are letters she writes to the people closest to her, namely her father, her mother, her brother, Zoey and Adam. Generally, she informs the addressees about how she wishes them to behave after her death, dealing with the proceedings regarding her funeral and giving them tips and pieces of advice as far as their future without her are concerned.

In *Before I Die*, the narrative situation is remained until the very end. Tessa narrates her story in the first person, from an internal perspective and in a reflector-mode until the very end. Stanzel argues that this presentation of the last moments of a dying person, dominated by the gradual loss of consciousness, very often happens in a stereotypical way: "An intense death scene such as this, which forces the reader, as it were, to experience the last moments of the dying person, can be very effective. The possibilities for doing justice to the individuality of the first-person character in this decisive moment are limited, however." (Stanzel 229)

Jenny Downham is able to succeed in remaining Tessa's individuality by enriching the last thoughts before her main character's death with certain memories of her past. Many of which seem commonplace and unimportant, yet they – out of whatever reasons – quite obviously have been of importance in and for Tessa's life:

> Six snowmen made of cotton wool.
> Six serviettes folded into origami lilies.
> Seven stones, all different colours, bound with a silver chain.
>
> There's sun in my teacup.
> Zoey stares out of the window and I drive out of town. The sky gets darker and darker. (Downham 325)

In addition to Tessa's thoughts and feelings, Downham also gives the reader information about the utterances of the people surrounding her. Throughout the novel, a large amount of dialogue scenes is presented. Accounting for more than fifty percent of the entire text, they enable the reader to get an idea of the character traits and emotions of the people Tessa encounters frequently. One example is the following conversation between Adam and Cal who are with her and discuss the state Tessa is in, in this way informing the reader of what is happening:

> "Are you sure she should be making that noise?"
> "I think it's OK."
> "It's different from just now."
> "Shush, I can't hear."
> "That's worse. That sounds like she can't even breathe."
> "Shit!"
> "Is she dying?"
> "Get your dad, Cal. Run!" (Downham 320)

Of particular importance seems to be the noticeable decline in scenic presentation in the novel. A reasonable explanation of this tendency seems to be the reflector-character's progressing disease. Initially, she actively takes part in the lives of the members of her family and her friends, talks to them and listens to their conversations. Towards the end of her life, however, the young woman retreats from family life. The passages in which the protagonist dwells on her own thoughts become longer, increasingly drawing the reader into her mind.

The presentation of the text mirrors her state of health. Her breath becomes shorter towards the end, so do the sentences on the last pages of the novel. At the same time, the space between the sentences grows and the amount of words per page therefore decreases. Tessa seems to fight death until the very end, until there is finally a repetition of the phrases “let them go” and “moments”, which are ultimately “all gathering towards this one”.

> The sound of a bird flying low across the garden. Then nothing. Nothing. A cloud passes. Nothing again. Light falls through the window, falls onto me, into me.
>
> Moments.
>
> All gathering towards this one. (Downham 327)

2. THEORETICAL BACKGROUND

2.1. Medicine

2.1.1. Leukaemia

2.1.1.1. The nature of leukaemia[19]

> Leukaemia is not a single cancer but a group of diseases representing malignant clones arising in developing blood cells. (Lilleyman 15)

Leukaemia is characterized by a disturbance in the production of normal white blood cells. This is caused by a breakdown of the control mechanisms, enabling the production and survival of a large number of abnormal white blood cells. Consequently, the vital tasks of the normal white blood cells remain unfulfilled.

The frequently used term "blood cancer" is misleading: "The cells of the blood are actually made in the bone marrow or the lymphatic system and it is a cancer of those organ systems rather than the blood itself that gives rise to leukaemia." (Lilleyman 16)

2.1.1.2. The types of leukaemia[20]

Indicating the type of blood cell being affected on the one hand and the speed of progression of the disease on the other hand, leukaemia can be classified as either lymphatic or myeloid as well as either acute or chronic. Therefore, the following four types of leukaemia are distinguished:

<u>The acute lymphatic or lymphoblastic leukaemia (ALL)</u>

It progresses rapidly and concerns the blood cells produced in the lymphatic system. More than 80 per cent of all children suffering from leukaemia are being affected by this type.

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[19] Lilleyman, John S. *Childhood leukaemia: The facts.* Oxford: Oxford Univ. Press, 2000.
[20] Lilleyman, John S. *Childhood leukaemia: The facts.* Oxford: Oxford Univ. Press, 2000.

The chronic lymphatic or lymphoblastic leukaemia (CLL)

It progresses slowly and concerns the blood cells produced in the lymphatic system. Cases of children suffering from this type of leukaemia are unheard of.

The acute myeloid or myeloblastic leukaemia (AML)

It progresses rapidly and the blood cells produced in the bone marrow are affected. This type of leukaemia is rather frequent among children.

The chronic myeloid or myeloblastic leukaemia (CML)

It progresses slowly and the blood cells produced in the bone marrow are affected. The percentage of children with leukaemia suffering from this type amounts to less than three.

2.1.1.3. The symptoms of leukaemia[21]

The following are the most frequent symptoms developed by children with leukaemia:

Fatigue and pale skin

These symptoms are directly linked to a lack of red blood cells.

Infections and fever

The shortage of normal white blood cells often results in an infection, accompanied by fever.

Easy bleeding or bruising

Since they are responsible for the arrest of bleeding, a lack of blood platelets causes nosebleeds, bleeding gums and small red spots on the skin.

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[21] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

Bone or joint pain

These symptoms can be explained by the "buildup of leukemia cells near the surface of the bone or inside the joint."[22]

Swelling of the abdomen

An enlargement of the liver and the spleen, caused by an accumulation of large quantities of leukaemia cells, leads to a swollen belly.

Loss of appetite and weight loss

This symptom is caused by a growth of the liver or the spleen, resulting in pressure on the stomach and therefore a limited amount of possible intake of food.

Swollen lymph nodes

Even though swollen lymph nodes are often a symptom of an infection, they are also a likely sign for spreading leukaemia cells.

Coughing or trouble breathing

One very common type of acute lymphoblastic leukaemia involves the thymus gland, whose augmentation causes pressure on the windpipe.

Swelling of the face and arms

An enlarged thymus also accounts for a swollen face, arms, neck and chest as well as headache, dizziness and the loss of consciousness. This is due to the pressure being put on a large vein connecting the head and arms with the heart.

Headache, seizures and vomiting

The spreading of leukaemia outside the bone marrow entails some additional symptoms: "About 5 % to 10 % of children have leukemia that has already spread to the central nervous system when they are first diagnosed. Headache, trouble concentrating, weak-

[22] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

ness, seizures, vomiting, problems with balance, and blurred vision can be symptoms of central nervous system leukemia."[23]

2.1.1.4. The types of samples[24]

Blood samples

The blood samples taken from a vein in the arm are used for blood counts and blood smears:

> A complete blood count (CBC) is done to determine how many of each type of blood cell is present in the blood. For a blood smear, a small sample of blood is spread on a glass slide and looked at under a microscope. Changes in the numbers of different blood cell types and in the way these cells look may make the doctor suspect leukemia.[25]

Bone marrow samples

A more reliable way of diagnosing leukaemia is looking at bone marrow cells. In order to be able to do this, bone marrow aspiration and biopsy are executed, taking samples from the back of the hip bone. At a later stage, both tests are frequently repeated in order to check the efficiency of the treatment.

Lumbar puncture

After disinfection, fluid is taken from between the bones of the spine with a hollow needle. "This test is used to look for leukaemia cells in the cerebrospinal fluid (CSF), which is the liquid that bathes the brain and spinal cord. A lumbar puncture can also be used to give chemotherapy drugs into the CSF to try to prevent or treat the spread of leukaemia to the spinal cord and brain."[26]

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[23] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

[24] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

[25] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

[26] American Cancer Society. "How is childhood leukemia diagnosed?" http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp (05/14/10).

2.1.1.5. The treatment of leukaemia[27]

Whereas fifty years ago more or less all children suffering from one of the two acute types of leukaemia died, advances in both treatment and care account for a survival of four out of five children today. Unfortunately, however, the treatments necessary in order to save the lives of the children often leave them with lasting side-effects.

Nowadays, it is the aim of treatment to "[…] achieve a state called remission where almost all leukaemia cells have been killed, allowing production of normal blood cells to resume. Further treatment is given to eradicate the disease completely and achieve a cure."[28]

As far as acute lymphoblastic leukaemia is concerned, an exact diagnosis is followed by four blocks of treatment.

Block 1: Remission induction

In order to eradicate the leukaemia cells, a combination of several drugs is used. This first, intensive phase of treatment lasts for a few weeks and aims at the restoration of the normal function of both the blood and the bone marrow.

Block 2: Central nervous system directed therapy

In the second phase, direct injection of drugs into the spinal fluid takes place. This is due to the fact that the barrier to the cerebro-spinal fluid cannot be penetrated by the drugs very well, making it possible for the leukaemia cells having reached this site to survive there.

Block 3: Delayed intensification therapy

The maintenance of the achieved remission requires further treatment: "Standard treatment involves two courses of powerful drugs given at roughly four and eight months from diagnosis. The drugs will affect the child's bone marrow and its ability to produce

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[27] Children with Leukaemia. "Treatments." http://www.leukaemia.org/about-leukaemia/treatments (04/28/10).
[28] Children with Leukaemia. "Treatments." http://www.leukaemia.org/about-leukaemia/treatments (04/28/10).

blood cells, leading to a fall in their blood count and associated problems such as infection and bleeding."[29]

Block 4: Maintenance therapy

In order to minimize the risk of a relapse, treatment in the form of daily tablets and monthly injections of chemotherapy drugs is maintained. Whereas this phase lasts for 26 months for boys, it only lasts for 14 months for girls. Children and their families should gradually be able to return to their normal lives.

2.1.1.6. The causes of leukaemia[30]

Even though scientists admit that the knowledge of the development of leukaemia is still very limited, they currently agree on the validity of the "two-hit hypothesis". "[It] proposes that initiating events take place whilst the child is still in the womb, with a second "hit" later in life triggering the development of full-blown leukaemia."[31]

In this case, the initiating event is one of a number of different genetic mutations which, however, in itself do not account for the development of the disease. After all, only less than one per cent of all children born with one of these mutations develop leukaemia later on in their lives. It is not before they are hit a second time that the disease arises.

On the one hand, there are factors which seem to increase the risk. Examples for these are ionising and non-ionising radiation as well as chemical and infectious exposure. On the other hand, there are factors which seem to decrease the risk. Examples for these are diet, folate and folate metabolism as well as infectious exposure, vaccination and breast feeding.

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[29] Children with Leukaemia. "Treatments." http://www.leukaemia.org/about-leukaemia/treatments (04/28/10).
[30] Children with Leukaemia. "What causes leukaemia?" http://www.leukaemia.org/about-leukaemia/what-causes-leukaemia (04/28/10).
[31] Children with Leukaemia. "What causes leukaemia?" http://www.leukaemia.org/about-leukaemia/what-causes-leukaemia (04/28/10).

Since the number of children developing leukaemia has steadily increased throughout the last century, scientists claim that "factors linked with our modern lifestyle"[32] are likely to be influential on the development of the disease.

2.1.1.7. The frequency of leukaemia[33]

> Leukaemia of one type or another is the commonest childhood malignant disease forming some 30 per cent of all children's cancers. (Lilleyman 15)

In the United Kingdom, the average annual number of new cases of childhood leukaemia amounts to 466. This number includes children developing the disease before turning 15. For unknown reasons, the number of boys developing leukaemia is about 10 per cent higher than the number of girls. More than 50 per cent of all children suffering from one of the four types of leukaemia are younger than five years old.

Age is an important factor as far as the incidence of leukaemia is concerned. For the most common type of childhood leukaemia, ALL, the following holds true: "The risk of acute lymphoblastic leukaemia (ALL) increases rapidly after birth, peaks around the third or fourth year of life and then declines."[34]

Some interesting tendencies also show on a global scale: The more affluent the country, the higher the incidence rate.

2.2. Psychology

2.2.1. The five Stages of Grief[35] by Elisabeth Kübler-Ross

Elisabeth Kübler-Ross was born in Switzerland on July 8, 1926. After her graduation from the University of Zurich in 1957, she continued her studies and started to work in the United States, where she completed her degree in psychiatry in 1965.[36]

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[32] Children with Leukaemia. "What causes leukaemia?" http://www.leukaemia.org/about-leukaemia/what-causes-leukaemia (04/28/10).
[33] Children with Leukaemia. "Incidence of childhood leukaemia." http://www.leukaemia.org/about-leukaemia/incidence-of-childhood-leukaemia (04/28/10).
[34] Children with Leukaemia. "Incidence of childhood leukaemia." http://www.leukaemia.org/about-leukaemia/incidence-of-childhood-leukaemia (04/28/10).
[35] Kübler-Ross, Elisabeth. *On Death and Dying.* London: Tavistock Publications, 1973.

In 1969, after her intensive work with the dying, Kübler-Ross wrote *On Death and Dying*. In this book she came up with a new pattern of adjustment, the five stages of grief: "In general, individuals experience most of these stages, though in no defined sequence, after being faced with the reality of their impending death. The five stages have since been adopted by many as applying to the survivors of a loved one's death, as well."[37]

Seen away from numerous articles, Kübler-Ross wrote over 20 books. Translations of which can be found in 30 languages. "She is a 2007 inductee into the National Women's Hall of Fame. She was the recipient of twenty honorary degrees and by July 1982 had taught, in her estimation, 125,000 students in death and dying courses in colleges, seminaries, medical schools, hospitals, and social-work institutions."[38]

Kübler-Ross died in Arizona on August 24, 2004.

2.2.1.1. The first stage: Denial and isolation

When being confronted with the diagnosis of a terminal illness, the patient's first reaction is very often an utterance like: "No, not me, it cannot be true." (Kübler-Ross, *On Death and Dying* 34) Kübler-Ross accounts for this in the following way: "Since in our unconscious mind we are all immortal, it is almost inconceivable for us to acknowledge that we too have to face death." (Kübler-Ross, *On Death and Dying* 37)

This stage is often characterized by the patients' seeing a large number of doctors, going through numerous examinations and expressing their opinion that the diagnosis they were given must be based on a report other than their own and therefore irrelevant to them.

Anxious denial shortly after the presentation of the diagnosis seems to be particularly strong in those cases where the patients are informed either at too early a stage, or too abruptly. This might either be due to the fact that the person relating the devastating

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[36] ---. "Elisabeth Kübler-Ross." http://en.wikipedia.org/wiki/Elisabeth_K%C3%BCbler-Ross (05/16/10).
[37] EKR Family Limited Partnership. "Biography." http://www.ekrfoundation.org/bio (05/16/10).
[38] EKR Family Limited Partnership. "Biography." http://www.ekrfoundation.org/bio (05/16/10).

information does not know the patient well enough, or feels the need to finish this "task" as quickly as possible.

However, at least partial denial is a natural and indeed very important phenomenon in the process of grieving. Interestingly, this holds true not only for those patients who are explicitly being given the diagnosis of a terminal illness by doctors already at the beginning of their disease, but also for those who come to realize this on their own at a later point in time.

The stage of denial is not restricted to the beginning of the grieving process. Due to the fact that it is impossible to face death all the time, it tends to come up occasionally also at later stages when the patients have already partially accepted their terminal illness.

Since denial is necessary and occasional daydreaming to be respected, Kübler-Ross stresses the importance of letting the patients decide themselves when and for how long they want to talk about the inevitable proximity of death: "Denial functions as a buffer after unexpected shocking news, allows the patient to collect himself and, with time, mobilize other, less radical defenses." (Kübler-Ross, *On Death and Dying* 35)

Isolation comes up much later. Kübler-Ross characterizes this stage in the following way: "He can then talk about his health and his illness, his mortality and his immortality as if they were twin brothers permitted to exist side by side, thus facing death and still maintaining hope." (Kübler-Ross, *On Death and Dying* 37)

Interestingly, when it comes to denial, patients frequently adapt their behaviour to that of their interlocutors. Whereas they are likely to face their illness and their upcoming death in conversations with people seemingly able to cope with the tragic reality, patients generally pretend to get well when talking to people unable to do so.

According to Kübler-Ross, the way a patient is being informed about his or her disease, the time he or she has left and finally the coping strategies he or she has acquired throughout life and therefore available when being confronted with the diagnosis determine how quickly the patient will be able to overcome the stage of denial.

2.2.1.2. The second stage: Anger

Kübler-Ross reports that after having, at least partially, overcome the stage of denial, her terminally ill patients very often come up with the question: "Why me?" (Kübler-Ross, *On Death and Dying* 44) They do not see and do not want to see why it should be time for them to leave everything they love behind if everybody else gets the chance to continue. They are confronted with the fact that they will not be able to do the things they had always planned to do and that business they had aimed at completing remains unfinished.

According to Kübler-Ross, for the members of the family as well as for the medical staff this stage is particularly difficult to cope with. After all, the patient's anger is not only directed against God, but also against people in their surroundings. Neither doctors, nor nurses can do as pleased, and the members of the family visiting are unlikely to be heartily welcomed. The family reacts to this, as Kübler-Ross describes, either with "grief and tears, guilt or shame, or avoid future visits, which only increases the patient's discomfort and anger." (Kübler-Ross, *On Death and Dying* 45)

The situation becomes extremely difficult if they take it personally and start avoiding the patient. After all, Kübler-Ross argues that the main reason for her patients' raising their voices is their fear to be forgotten. Therefore, a decreasing visiting time understandably nourishes the sufferer's anger, resulting in even less bearable behaviour not only towards members of the family and friends, but also the medical staff. This vicious circle can be avoided by taking time for them, by listening to all they have to say, by showing as much understanding as possible and by – very generally – paying respect to them.

A frequent and potentially very strong source of anger is the loss of control. The only solution to this problem seems to be to give the patients suffering from the lack of power the opportunity to actively decide on what remains to be decided. Examples of the type of decisions that might be delegated to the patients are the time and length of visits as well as the time of cleaning of the bed sheets.

2.2.1.3. The third stage: Bargaining

The third, least well known, but in certain periods of time very valuable stage involves bargaining. Kübler-Ross describes that in this phase the patients hope that an agreement can be made, the ultimate aim of which being to postpone death.

This stage is characterized by wishes. These wishes change over time, mostly starting out with an extension of life and finally reaching a certain amount of time without pain. If their wishes are being granted, patients promise – depending on their religious beliefs – to either dedicate their souls to God or to devote their bodies to science.

Kübler-Ross compares this behaviour to the one of children, realizing that anger does not get them what they desire and desperately hoping that "being good" will turn out more successful: "If God has decided to take us from this earth and he did not respond to my angry pleas, he may be more favourable if I ask nicely." (Kübler-Ross, *On Death and Dying* 72)

Interestingly, the bargain does not only include good behaviour on the one hand and a reward on the other hand, but also a voluntary limitation: "The bargaining is really an attempt to postpone; it has to include a prize offered "for good behaviour", it also sets a self-imposed "deadline" [...], and it includes an implicit promise that the patient will not ask for more if this one postponement is granted." (Kübler-Ross, *On Death and Dying* 73)

However, Kübler-Ross states that she has never come across a patient who turned out to keep his or her promise. Whenever the suffering had come to the point in time they had wished to reach and they were therefore granted postponement, they started bargaining again, asking for even more time.

2.2.1.4. The fourth stage: Depression

Kübler-Ross identifies two types of depression. On the one hand, the patients have to cope with the feeling of current loss. They have to acknowledge that weakness causes them to lose the ability to function the way they did before, resulting in a deterioration of their entire lifestyle. Additionally, the patients are very often confronted with financial problems due to the high costs of treatment and hospitalization. On the other

hand, the patients are confronted with the knowledge of future loss. They are very much aware of the fact that they are going to lose everybody they have ever known and everything they have ever had within a short amount of time. Kübler-Ross argues: “If I were to attempt to differentiate these two kinds of depressions, I would regard the first one a reactive depression, the second one a preparatory depression.” (Kübler-Ross, *On Death and Dying* 76)

Whereas Kübler-Ross argues that in the phase of reactive depression it is good to try to cheer the patients up and that words are very likely to be helpful, she is of the opinion that in the phase of preparatory depression it is not advisable to make efforts as far as cheering up is concerned and that there is no general need for verbal communication: “In the preparatory grief there is no or little need for words. It is much more a feeling that can be mutually expressed and is often done better with a touch of a hand, a stroking of the hair, or just a silent sitting together.” (Kübler-Ross, *On Death and Dying* 77)

In order to be able to emotionally prepare it is important for the patient to get the possibility to be both sad and silent. Not only the members of the family and friends, but also the medical staff have to bear this is mind. After all, it becomes extremely difficult for the patients if they want to prepare for their deaths but are not given the possibility to do so by being expected to be jovial, hopeful and in a fighting mood until their very end: “It is this discrepancy between the patient's wish and readiness and the expectation of those in his environment which causes the greatest grief and turmoil [...].” (Kübler-Ross, *On Death and Dying* 78)

2.2.1.5. The fifth stage: Acceptance

After the terminally ill have gone through all the other stages more or less intensively and more or less successfully, what remains for them to do is to quietly expect the inevitable.

Being aware of the fact that it is a possible source of misunderstanding, Kübler-Ross clarifies the term with which she characterizes this stage: “Acceptance should not be mistaken for a happy stage. It is almost void of feelings.” (Kübler-Ross, *On Death and Dying* 100)

When reaching this final phase, the dying generally need an increasing amount of sleep and verbal communication is, step by step, replaced by nonverbal communication. This stage in the grieving process seems to be much more difficult to cope with for the members of the family and friends of the suffering person than for the patients themselves. The latter loses interest in the world, a process often not understood by the former.

Kübler-Ross points out the individuality of the patients that shines through in the entire grieving process and that seems to be particularly striking when it comes to the very last stage, namely acceptance:

> One kind of patient will achieve it with little if any help from the environment – except a silent understanding and no interference. (Kübler-Ross, *On Death and Dying* 105)

> Others, less fortunate ones, may reach a similar state of body and mind when they are given enough time to prepare for their death. They will need more help and understanding from the environment [...]. (Kübler-Ross, *On Death and Dying* 105)

2.2.2. The Needs of the Dying[39] by David Kessler

Intensively having worked with Elisabeth Kübler-Ross and having been the co-author of *On Grief and Grieving* and *Life Lessons*, David Kessler sees it as his "mission to keep his promise to carry her legacy into the future so the work can continue." (Kessler, *The Needs* 225)

In 1995, Kessler started *The Rights of the Dying*, which was published in 1997. After insistent and repeated feedback from his readers, communicating that they did not like the title, it was finally changed to *The Needs of the Dying*: "It may seem like just a matter of semantics, rights vs. needs, yet I have heard readers say that "the rights" sounded like a call to arms rather than a pathway to comfort." (Kessler, *The Needs* 210)

Currently living in Los Angeles, Kessler is the "vice president of Patient Support Care Services for a three-hospital system in Los Angeles Country. His programs serve some

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[39] Kessler, David. *The Needs of the Dying*. New York: HarperCollins Publishers, 2007.

of the poorest of the poor in Los Angeles and he is responsible for "End of Life" education for 900 physicians and 2000 nurses." (Kessler, *The Needs* 226)

2.2.2.1. The need to be treated as a living human being

David Kessler stresses the importance to keep in mind that terminally ill people are alive until the very moment of their death and have to be treated accordingly: "To do any less than treat the dying as living human beings until death is to take from them their self-images, their stories, their hopes, and their dignity." (Kessler, *The Needs* 2)

In order to be able to complete their lives, the dying have to be given the possibility to make their own decisions, express their desires and take part in conversations as long as possible: "Often we think of them as their diseases, by acting as if they are incapable of making their own decisions, by negating their opinions, by overlooking their desires, by withholding information from them, and by omitting them from conversations." (Kessler, *The Needs* 2)

Since stories represent the images the dying have of themselves, it is important to give them the possibility to tell their stories. The thought that these stories will survive the death of the individual has a highly comforting and reassuring effect. Interestingly, this personal picture being drawn in the stories is very often one full of life. Kessler argues that "[w]e cling to that part of ourselves that is indefinable and changeless, that does not get lost and does not deteriorate with age or disease." (Kessler, *The Needs* 4)

Even though the illness as well as the effects the illness has on the physical appearance of the patients might make this a highly challenging task, it is very important to keep seeing the dying as complete human beings. After all, Kessler argues that "[s]eeing beyond the illnesses is one of the most meaningful gifts we can give them." (Kessler, *The Needs* 6) He is of the opinion that this can most easily be achieved by "looking into the changeless eyes" (Kessler, *The Needs* 6) of the loved person.

2.2.2.2. The need to maintain a sense of hopefulness, however changing its focus may be

It is only in the initial phase of a terminal illness that patients hope to recover. Usually, their hope shifts, making them, for example, hope to die in peace and without pain and not to be alone but with loved members of the family or friends.

Being convinced of the fact that hope and fear always accompany a life-threatening illness, Kessler states: "The two emotions are as inevitable as they are constant, right up to the moment of death. If we take away someone's hope, we leave them with nothing but fear." (Kessler, *The Needs* 7)

Kessler argues that hope should never be challenged, but protected and cultivated. He is of the opinion that this holds true for seemingly hopeless situations as well, giving the following reason: "Hope is a journey, not a destination; its value lies in the exploration. Hope is the way we live life, and the journey of hope should last until we end." (Kessler, *The Needs* 8)

2.2.2.3. The need to be cared for by those who can maintain a sense of hopefulness, however changing this may be

Many doctors see death as the enemy and a manifestation of their failure and, therefore, they fight it. According to Kessler, they tend to give up hope as soon as they realize that they cannot help the patient medically any more. However, it is important to keep in mind that "[…] hope is much more than an optimistic request, a guarantee of a cure or remission. Hope is a part of who we are, a part of our lives, and a vital part of our deaths." (Kessler, *The Needs* 10)

Unfortunately, physicians often disapprove with their patients seeking alternative treatment and refuse further care in case they do so despite their – often unjustified – discontent.

2.2.2.4. The need to express feelings and emotions about death in one's own way

Both for the dying as well as for their family and friends it is highly important to express emotions honestly. Kessler argues: "Even though we don't know how to say good-bye and we don't want to say good-bye, if we can break through our reluctance

and find the courage to express our emotions, we can bring our relationships to new levels. We can complete them." (Kessler, *The Needs* 18)

Due to their fear of saying something either too trivial or too threatening, many people are afraid of talking to people challenged with a terminal illness. According to Kessler, there are no generally valid rules and each situation needs individual assessment. This makes talking about death with terminally ill people an uncertain undertaking: "Talking about death is like stepping into uncharted territory. It can be liberating and cathartic." (Kessler, *The Needs* 21)

In addition to being honest and asking the patients for their preferred topic, Kessler suggests relying on the patients' telling what is necessary for the listeners to know: "Listen to them complain. Listen to them cry. Listen to them laugh. Listen to them reminisce. Listen to them talk about the weather or talk about death. Just listen." (Kessler, *The Needs* 22)

We have to accept what they are telling us since they have the need and right to think, believe and feel the way they want and express their emotions the way they choose to.

In order not to regret the discomfort in the relationship that things remaining unspoken bring, unfinished business needs to be completed. In this way, relationships are made current: "A current relationship is one in which both have said everything they need to say to each other, whether it is supportive or challenging." (Kessler, *The Needs* 29)

Kessler stresses the value of the loved ones' expressing the sadness in front of the dying. Not only does it help the members of the family and friends to be comforted, but also the suffering to be able to comfort their loved ones and relieve their pain. Since hearing is believed to be among the last senses to disappear, it is suggested to keep talking and expressing emotions, even if the dying person is no longer able to respond.

2.2.2.5. The need to participate in decisions concerning one's care

In order to be able to die their own deaths, it is necessary for the terminally ill to make a number of decisions. The most fundamental one seems to be whether or not they do at all want to spend further thoughts on their deaths. In case they do want to actively face their situations, they have the right to decide about all matters concerning their care as

well as their deaths, the application of aggressive treatment being one particularly important and potentially controversial issue.

2.2.2.6. The need to be cared for by compassionate, sensitive and knowledgeable people

It is important for the dying to be surrounded by people who try to meet their needs. Not only family members and friends, but also physicians and other members of the medical staff have to understand the particular situation the terminally ill find themselves in and act as tactfully and lovingly as possible. After all, "[p]eople who are dying need tender, loving care and caregivers who will honor their needs. How a person dies reflects their caregiver's beliefs more than their own."[40]

2.2.2.7. The need for continuing medical care, even though the goals may change from cure to comfort goals

It seems to be a general problem that people often do not make their wishes concerning the use of medical treatment clear until it is too late and they are no longer able to express what they want. Therefore, Kessler suggests informing members of the family, friends and the medical staff about one's wishes concerning the level of treatment or signing an Advanced Directives or a Durable Power of Attorney for Health Care.

In many cases, the appointment of a proxy seems to be a valuable decision. Due to legal issues and their being used to fighting, doctors generally do everything to keep the patient alive. It is therefore necessary to choose a strong proxy who is willing and able to stand up for the patient's wishes. "The care most people receive reflects their doctors' beliefs and values. It is crucial to establish a relationship with a physician who shares your values and beliefs." (Kessler, *The Needs* 55)

Kessler emphasizes that informing the patient does not only include telling him or her what cannot be done (anymore), but also what (still) can be done. Additionally, the patients have got the right to change their goals as often as they feel the need to do so. Their wishes must be respected and it is always the sufferer's last decision that counts.

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[40] Kessler, David. "The Needs of the Dying." http://www.cmellc.com/geriatrictimes/g010540.html (05/19/10).

2.2.2.8. The need to have all questions answered honestly and fully

Since sufficient information is necessary in order to be able to make decisions, answers to all questions asked have to be given. Unfortunately, caretakers often think that withholding parts of the truth save the patients from emotional suffering and, in consequence, do not tell them everything they know. Sometimes it is the doctors and sometimes the members of the family or friends who do not like to inform the patients about their actual situation: "Everyone means well, but withholding knowledge from those faced with life-threatening illnesses keeps them from participating in all decisions concerning their care and excludes them from the final chapters of their own lives." (Kessler, *The Needs* 43)

2.2.2.9. The need to seek spirituality

When being confronted with the end of life, people generally hope to find that there is a reason for the things happening. It is spirituality that in this very moment helps to realize that there is order and meaning to the world and every individual's life.

Whereas people generally tend to be looking outward throughout their lives, when being confronted with the knowledge of the proximity of their death they start looking inward. What often starts is the phase of an intensive examination of the lives lived so far, accompanied by numerous questions:

> Where do I go from here? Have I accomplished all that I was supposed to? Am I still whole and intact, despite my disease-ravaged body? Will I continue in one form or another? How do I find peace, the only thing that really matters now? Who am I really? Am I more than just a physical body? Do I have a spirit that will live on? (Kessler, *The Needs* 100)

Kessler argues that "[u]pon developing a genuine desire to explore their spiritual selves, people go through five stages of spiritual reconciliation: expression, responsibility, forgiveness, acceptance, and gratitude." (Kessler, *The Needs* 102)

The first stage is characterized by expression. In order to find inner peace it is necessary to express all the existing feelings, particularly the "ugly" ones, and to release anger, no matter whether directed towards people in the individual's life or God. The stage following is about taking responsibility. It is one step on the way to spirituality to

realize that even if – rather obviously – not for the disease, one is indeed responsible for the actions taken in the course of his or her life.

There are several reasons for people taking the third step on their way to spirituality, namely forgiving themselves and others. Not only does the knowledge of their early death and the fact that within a very limited amount of time anything will be over anyway make them realize the absurdity of their holding on to hatred. Also, people want to die without open wounds and be remembered as kind and forgiving people.

At a certain point, the fight has to end and it has to be accepted that life is complete, despite the things remaining undone. Kessler emphasizes that having reached the stage of acceptance does not include finding the thought of death pleasant: "We think that to accept something is to somehow make it good or desirable. However, I think we can own our feelings and accept what is happening. I believe individuals on their deathbed can honestly say, 'I don't want to die' yet accept that they are dying." (Kessler, *The Needs* 106)

The fifth and final step on the road to spirituality is the feeling of gratefulness for life with all its good and bad sides.

Kessler emphasizes that due to the fact that spirituality does not affect the body, but the mind and the spirit, it should not be misunderstood as a cure. Instead, he claims that spirituality is "our reconnection with ourselves, with others, and with life, even in the face of death. It is our seeking of peace." (Kessler, *The Needs* 111)

2.2.2.10. The need to be free of physical pain

> Many people insist that they don't fear death, but they are terrified by the painful process of dying. (Kessler 59)

Obviously, it is one of the major aims of the medical system to make sure that the patients' need to be free of pain is being met as much and as often as possible.

> The Agency for Health Care Policy and Research, a branch of the U.S. Department of Health and Human Services, determined that pain could be controlled in 90 percent of cancer patients. Unfortunately, too many people remain in pain: The same agency found that 42 percent of cancer patients received inadequate pain medication. (Kessler 62)

According to Kessler, the reasons for undermedication are manifold: On the one hand, the physicians' knowledge about pain in general and each individual's pain in particular is very limited. On the other hand, they fear – often unjustified – that too high a dose might lead to their patients' addiction and legal consequences for them.

In order to fight pain as successfully as possible, Kessler suggests communicating clearly about the pain, informing the medical staff about the personal pain history and not to be too timid when it comes to asking for pain relief. Just as pain is subjective, cannot be measured and the individual reactions to it vary, also the coping strategies that produce relief differ from patient to patient. It is therefore advisable for the suffering to try various alternative means of pain control in order to find out what works best for them: "Some people use prayer, some meditation, others visualization – imagining themselves on a beautiful beach in Hawaii, looking up at the blue sky. Still others visualize the inside of their bodies, watching as their own endorphins knock out the pain." (Kessler, *The Needs* 76)

According to Kessler, even though often very hard to understand, pain is a helpful assistant in the process of dying. This is due to the fact that "[w]e can detach from all that we have known only if pushed to do so by a powerful force. Pain may be the force that helps us to separate and let go of life." (Kessler, *The Needs* 79)

2.2.2.11. The need to express feelings and emotions about pain in one's own way

Patients tend to react to physical and emotional pain either with anger, or with depression. These emotions being equally justified and understandable, the dying have the need and right to express both of them, even if this is very often uncomfortable for members of the family, friends and the medical staff to witness. People tend do prefer the ailing to suffer silently rather than to cry and rage, leaving them with a feeling of helplessness. However, it is not up to the terminally ill to have consideration for this. After all, according to Kessler, "[t]he only way out of the pain is through the pain." (Kessler, *The Needs* 91)

Since pain has to be gone through at some point, Kessler stresses the necessity to consciously feel and express it at the very moment of its occurrence: "We cannot take away the pain that death causes, but if we experience it fully, we can prevent the wounding that so many people feel when pain is not dealt with as it occurs." (Kessler,

The Needs 92) It is impossible to avoid pain completely, it can only be delayed – and prolonged.

At some point, everybody fears pain. One way of reducing this fear is to inform and educate the patients about what lies in front of them. It does not only help them to know which effects their disease will have on their bodies, but also of which nature the pain they have to expect will be and which coping strategies they can rely on. In addition, various forms of distraction have been proven to be extremely helpful, both on a physical as well as on a psychological level. Finally, reassurance is a successful way of reducing fear. It is important for the patients to be told that their physicians will not run out of possibilities to relieve their pain.

2.2.2.12. The need of children to participate in death

Just as adults, also children have the need and right to say good bye to their loved ones. In order to be able to do this, they have to learn that death is a natural thing and a part of life: "Children who do not learn that every spring must eventually give way to a winter and that every life must produce a death have difficulty coping with loss." (Kessler, *The Needs* 116)

Kessler emphasizes that, just as children have to be taught about life, they also have to be taught about death. Obviously, this task is a very challenging one, given that the majority of adults feel uncomfortable as far as thinking and talking about the end of life is concerned. Nevertheless, it is of high importance to address this topic, ideally already before somebody is in the process of dying or has died. This seems to be particularly important, because what they imagine without being informed about the actual happenings is often worse than the reality and appropriate conversations can therefore spare them fear and self-reproaches.

Kessler stresses that the most important thing to remember when leading a conversation with a young child is to be honest. All questions asked should be answered according to the adult's own beliefs and he or she is to admit that some questions have to remain unanswered.

Since children should neither be told too much, nor too little, it seems to be the best approach to give them a little bit of information at a time and then, depending on their

reaction, to either leave the topic until they ask for details, or to tell them more immediately.

When a death in the family occurs it is necessary to reassure the child that not everybody will die at once, that they will be cared for and are loved and that normal life will eventually return. Kessler formulates the following four steps to help children grieve:

1. Help them understand and make sense out of what has happened or is happening.

2. Help them grieve or express their emotional response to the present or anticipated loss.

3. Teach them that life goes on.

4. Help them commemorate the loss, whether formally or informally. (Kessler 127)

2.2.2.13. The need to understand the process of death

If they do want to know it, the dying have the right to know what lies in front of them and to be given as much information as possible. Kessler emphasizes that every death is unique, but "[w]hile there is no guaranteed way to know when death is close or to predict the moment of death, there are several common signs of approaching death." (Kessler, *The Needs* 137)

Generally, as death approaches, the amount of sleep increases, whereas the intake of both food and beverage decreases. Further signs of the proximity of death are incontinence, changes in breathing, fever and sweating. Moreover, the patients often become restless, not finding a comfortable position in their beds any longer. Their senses decrease and death rattle sets in. This is a sound resulting from "the body's inability to clear or cough up saliva or other secretions which may collect in the back of the throat, lungs, or upper airways." (Kessler, *The Needs* 149)

2.2.2.14. The need to die in peace and dignity

> Dying with dignity means knowing that your death will be just as meaningful and purposeful as your life has been. It means dying the way you want to die, not the way others have deemed proper or worthy for you.

> Dying with dignity means being you, just as you have always been, right up to the end. (Kessler 152)

In order to meet the need of peace and dignity, the dying have to be seen and treated as whole human beings, alive until the very moment of their death. This does not only mean including them in conversations and the decision-making process as far as care and death are concerned. The ill person also has to be involved in all other aspects of his or her family's life. According to Kessler, reality unfortunately often looks differently: "We tend to equate a loss of physical capability with a lack of mental and emotional capabilities, and then we treat the dying as less than the living." (Kessler, *The Needs* 14)

Unfortunately, in many cases the medical system is to blame for a loss of dignity. It is not only the frequent occurrence of depersonalization of the patient that brings it about, but also the fact that death is not generally being acknowledged as a normal part of life but fought as if it was the enemy.

According to Kessler, another common source of the loss of the dying's dignity lies in the members of the family or friends forcing the terminally ill to do what they believe to be good, irrespective of their wishes. Caretakers are never to forget that the ailing have the need and right to make their own decisions up to the very end.

As far as the need to die in peace and dignity is concerned, Kessler summarizes: "Human beings deserve tenderness, dignity, honesty, compassion. And most of all, they deserve an acknowledgement that life ends at death and not a moment before." (Kessler, *The Needs* 17)

2.2.2.15. The need not to die alone

In addition to the inevitable fact that death is by its nature something that everybody has to go through alone, the dying are often additionally being isolated by their caretakers, both physically and emotionally. Mostly due to helplessness and anxiety, this is on the one hand done by their sitting in the waiting room rather than at their loved ones' bedside and on the other hand by not talking and listening to them.

Kessler emphasizes that, verbal communication not always being necessary, it is important to just be with them, holding their hands and letting them know that they are not alone. "We learn that the only thing that can sometimes comfort us or our loved

ones is our presence. There are no instructions; it's a process of trial and error, learning as you go. We have the need not to die alone. It's much better for the dying and for the living if we do it together." (Kessler, *The Needs* 175)

2.2.2.16. The need to know that the sanctity of the body will be respected after death

When approaching death, people obviously come to realize that they are about to lose control and are particularly worried about what might happen to their bodies after death: This seems to be directly linked to the significant change that has taken place in the last decades: Whereas in former times people died at home and were cared for by their families not only before, but also after death, nowadays the process of dying usually takes place in hospital and hospices. It is strangers who fulfil the tasks formerly done by the loved ones of the deceased and therefore it is important to reassure the patients that their bodies will be treated respectfully.

Kessler stresses the importance of the remaining to have some quiet moments alone with the recently died person. They might want to spend this time talking to them, touching them and therefore having the possibility to realize – as far as this is possible at that stage – their death and to say good bye.

Since they provide them with certain, often very clear structures, rituals are important for the grieving family members and friends: "The funeral, the final telling of the deceased's story, helps us to accept the reality of death." (Kessler, *The Needs* 181)

3. A PHENOMENOLOGY OF THE PROTAGONIST'S LEUKAEMIA

The representation of the main character's disease, of its development over time as well as of the treatment happens in an interesting and often detailed way and seems to be of importance in connection with the topic of my paper. Not only does the author give specific information about the different stages of Tessa's disease, but she also gives the exact names of the drugs the girl has to take as well as of the medical instruments that are used.

The novel starts in early September, approximately eight months before the main character's death in April. This can be inferred from Tessa's remark that "it's two hundred and seventeen days until Easter" (Downham 28) and "one hundred and thirteen days until Christmas." (Downham 28)

The reader is informed about the fact that Tessa, whose birthday is in May, was diagnosed acute lymphoblastic leukaemia (see chapter 2.1.1.2.) at an age of 12 in one of the winter months four years before the novel's opening. She was required to leave school at the age of 14.

After her noticing bruises on her spine and due to her "flu-like illness which lasted for weeks and didn't ever seem to go away," (Downham 190) her father took her to the doctor and started to try to get to the bottom of his daughter's illness.

It was after a long time span of hope for a complete cure that approximately six weeks before the narration's start Tessa and her father were given sad information about the development of the disease. Even though the reader remains uninformed about any further details, it seems obvious that they were told that no cure could be expected any longer and that Tessa's death was inevitable and to be expected in a limited space of time.

Tessa shows many of the typical symptoms of leukaemia (see chapter 2.1.1.3.). According to her own descriptions at the beginning of the novel Tessa has a "skeleton face and [a] bald head." (Downham 47) Moreover, her "fingers are just bones and [her] skin is practically see-through." (Downham 5) She has got "puckered skin on [her]

chest," (Downham 22) also the rest of the surface of her body being a manifestation of her illness and its treatment: "I still have red patches on my stomach. And on my thighs. My skin is as dry as a lizard's, however much cream I smooth in. On the inside of my arms are the ghosts of needle marks." (Downham 14)

However, heavy drugs have left their marks not only on her skin, but also on her entire body: "I used to look like an ugly dwarf. My skin was grey and if I poked my tummy it felt like an over-risen lump of bread dough and my finger disappeared into its softness. Steroids did that. […] Since I stopped taking them I've started to shrink. […] I'm retreating, ghost-like, away from myself." (Downham 33)

Tessa's illness seems to make every single aspect of her life impossible to live in a careless way. She constantly has to pay attention to what she is doing. After all, her disease and its treatment cause Tessa to often feel weak and tired, to spend a lot of time in bed resting and require her not to overexert herself: "If I use up too much energy, I always pay for it later." (Downham 9)

Moreover, her illness forces Tessa to stick to a special diet which, among other things, does not allow Tessa to drink alcohol or eat any sugar or dairy products. Additionally, her father feeds her with vitamins:

> Vitamin E helps the body recover from post-irradiation anaemia. Vitamin A counters the effects radiation has on the intestine. Slippery elm replaces the mucous material lining all the hollow tubes in my body. Silica strengthens the bones. Potassium, iron and copper build up the immune system. Aloe vera is for general healing. And garlic – well, Dad read somewhere that the properties of garlic are not yet properly understood. He calls it vitamin X. All washed down with unprocessed orange juice and a teaspoon of unrefined honey. (Downham 56)

Due to the fact that she suddenly starts suffering from headaches, she has to undergo a painful lumbar puncture (see chapter 2.1.1.4.) in addition to the regular blood counts. After meanwhile having fainted in her neighbour's garden, she is called into hospital for a discussion of her disease. Tessa describes the situation in the hospital's waiting room:

> The usual suspects are here – the hat gang in the corner plugged into their portable chemo and talking about diarrhoea and vomiting; a boy clutching his mum's hand, his fragile new hair at the same stage as mine; and a girl with no eyebrows pretending to read a book. […] She sees me staring and

> smiles, but I'm not having any of that. It's a rule of mine not to get involved with dying people. They're bad news. (Downham 51)

Tessa and her father are informed about the fact that the lumbar puncture showed that Tessa's condition has deteriorated: The cancer has spread to the spinal fluid. The medical doctor shows them slides, telling them that "Tessa may respond to intensive intrathecal medication" (Downham 53) and suggesting "methotrexate and hydro-cortisone for four weeks," (Downham 53) arguing that a maintenance programme (see chapter 2.1.1.5.) could be continued in case it was successful.

When the doctor informs them about the seriousness of Tessa's situation, she makes use of her method of distraction in order to fend off the bad news from her: "Outside the window, the first rain of the day spatters against the glass. A leaf caught by a gust of wind rips, then flares red and gold as it falls." (Downham 53)

However, this is also the moment in which Tessa decides that she does not want to die before having lived properly, that she wants to take her life into her own hands and makes the decision to stop heavy treatment in order to be able to experience the things she feels she needs to do before her death:

> I've been ill for so long, puffed up and sick, with patchy skin, flaky fingernails, disappearing hair and a feeling of nausea that permeates to my bones. It's not fair. I don't want to die like this, not before I've even lived properly. It seems so clear to me. I feel almost hopeful, which is mad. I want to live before I die. It's the only thing that makes sense. (Downham 54)

When Tessa gets a headache and feels dizzy and sick in October, the intake of paracetamol does not save her from a collapse. In hospital, she is informed about the fact that the reason was hypercalcaemia, which is "a condition where your calcium levels become very high. We're giving you bisphosphonates, which will bring those levels down." (Downham 76)

Tessa describes her fingers as "thin and white, like vampire hands that could suck everyone's heat away." (Downham 78) At the end of the month Tessa suffers from aching bones and the frequent feeling of dizziness. She loses her taste and is aware of the fact that her appearance is changeable. This becomes obvious when she worries about meeting Adam unexpectedly in the garden: "Yesterday I looked like a smack-head because my skin seemed to be turning yellow. I put earrings in last night to try and

counteract the effect, but I forgot to check my face this morning. Anything could've happened during the night." (Downham 84)

The reader is also given a description of one of Tessa's regular blood tests, carried out by her nurse Philippa:

> She gets gauze and antiseptic spray from her medical case, puts on sterile gloves and holds my arm up so she can clean around the portacath. […] I lift my arm so she can draw blood through the portacath. […] She draws blood into a syringe and discards it. […] She draws a second syringe, transfers it to a bottle and scribbles my name in blue ink on the label. (Downham 105)

In this medical condition, Tessa says about herself: "I'm half robot, with plastic and metal embedded under my skin." (Downham 106)

From December onwards, she is often short of breath and sweats at night. She is changing between being hot and cold, frequently exhausted and comments on the unusual texture of her saliva, a typical symptom of people suffering from leukaemia: "My spit looks slimy, is pulled so slowly towards the plughole that I have to chase it down with more water from the tap." (Downham 173)

A heavy nosebleed requires the doctor to pack "sterile cotton into [her] nose" (Downham 222): "I feel as if I've eaten a sanitary towel; my mouth is dry and it's hard to breathe." (Downham 222)

In addition to numerous platelet transfusions and some lumbar punctures, Tessa also has to undergo a bone-marrow transplantation.

The following quotation clearly indicates the significance the medical service has in her life. After all, much time and thought is required in order to be informed about the different layers of the hospital building as well as Tessa proves to be:

> I find the layers of a hospital strangely reassuring. This is a duplicate world with its own rules and everyone has their place. In the emergency rooms will be the young me with fast cars and crap brakes. […] In the operating theatres are the people who mucked around with air rifles, or who got followed home by a psychopath. […] And in bed, deep inside the building, are all the headaches that won't go away. […] In the Marie Curie Ward on the fourth floor are the kids with cancer. Their bodies secretly and slowly being consumed. And then there's the mortuary, where the dead lie in refrigerated drawers with name tags on their feet. (Downham 219)

Twelve days after a blood transfusion, she gets anaemic on Valentine's Day: "It's getting harder to breathe. The shadows under my eyes have deepened. My lips look like plastic stretched over a gate. Last night I woke up at two in the morning. My legs were hurting, a dull throbbing, like a toothache. I'd taken paracetamol before going to bed, but I needed codeine." (Downham 230)

She sleeps very often, gets weaker and weaker and needs help increasingly frequently: "I get my coat. Adam finds my boots, scarf and hat, and helps me down the step." (Downham 236)

In March, she collapses because of an infection and traces of the disease are found in her peripheral blood. The doctor informs Tessa about the fact that her chances to live for another eight weeks are rather limited. She says about herself that she is aware of the fact that she looks "like a pile of bones covered in cling film." (Downham 260)

Even though she had been aching before, she is overwhelmed by the pain she has to temporarily suffer from in the final stages of her life: "I didn't know it would hurt this much. I didn't know that everything good that's ever happened in my life would be emptied out by it." (Downham 253)

Breathing becomes difficult for her and in order to maintain the blood count, it is necessary for Tessa to be rigorous with medical intervention. In April, she is increasingly at risk of becoming anaemic because her blood transfusions last for a decreasing number of days.

The presence of the illness and its treatment in her life become obvious in the situation in which she, in a burst of anger, throws various things out of the window: "Duvet, sheets, blankets, all out. Medicine bottles and boxes from my bedside table, syringe driver, Diprobase cream, aqueous cream." (Downham 270)

After having made the decision not to spend the last days of her life in hospital but at home, she has a conversation with Philippa about both the things she has to expect in her final days and minutes as well as possible pain relief:

> You won't want to eat much from now on. You'll probably want to sleep a lot. You might not want to talk, but you may feel energized enough for good ten-minute chats between sleeps. You may even want to go downstairs or outside if it's warm enough, if your dad is able to carry you. But mostly

> you'll sleep. In a few days you'll begin to drift in and out of consciousness, and at this stage you may not be able to respond, but you'll know people are with you and you'll be able to hear them talk to you. Eventually you'll just drift away, Tess. (Downham 280)

Tessa is very tired, always cold and does not have any appetite. She sleeps a lot, has to be carried and finally even loses the strength to sit up: "I can't be bothered to move. The sun grinds into my brain and everything aches." (Downham 297)

At the very end, Tessa even hurts when being touched and has to be given Oramorph. She is aware of her physical decline: "I stink. I smell myself farting. I hear the ugly tick of my body consuming itself. I'm sinking, sinking into the bed." (Downham 317)

She loses the feeling for time, becomes increasingly confused, dreams strange things and cannot keep her own memories and the memories revealed by others apart. She is no longer able to talk, but hears the people by her side and sees colours while they are talking. "I hear only the fraction of things. Words fall down crevices, get lost for hours, then fly back up and land on my chest." (Downham 316)

She feels like falling and "can't hold onto anything." (Downham 318) At least according to her father, Tessa finally falls unconscious, but is still able to hear the conversations between her father, her brother and her boyfriend, who are with her at her deathbed and witness the girl's death rattle (see chapter 2.2.2.13.):

> "I hate that noise. It sounds like it's hurting her."
> "It's not, Cal. She's unconscious. She's not in pain."
> "Adam said she could hear us. How can she hear us if she's unconscious?"
> "It's like sleeping, except she knows we're here. Sit with me, Cal, it's all right. Come and sit on my lap. She's peaceful, don't worry."
> "She doesn't sound peaceful. She sounds like a broken boiler." (Downham 322)

4. COPING WITH PHYSICAL PAIN

> It's like electricity, as if my spine got jammed in a toaster and the doctor's digging it out with a blunt knife. (Downham 38)

In contrast to the members of her family and her friends, Tessa does not only have to cope with the emotional pain that goes hand in hand with the knowledge of her impending death, but also with the physical pain accompanying her disease.

Despite taking drugs, Tessa is not always free of pain. In the course of time, she seems to have learned to develop certain strategies to cope with her physical pain and to enlist assistance not only of the members of her family and her friends, but obviously also of the medical staff.

Generally, Tessa seems to have become accustomed to blood and flesh, not being – just to mention one striking example – particularly worried about her heavy nosebleed. She deals with it extraordinarily bravely and only complains about and is afflicted with the fact that it keeps her from meeting her boyfriend. In spite of her constant indisposition – even laughing causes her pain – she is often able to savour the moment: "I haul myself up, even though my arms ache. I want to see inside planes too. I want to watch the wind and catch birds in my fist." (Downham 58)

Whereas Tessa does not stick to the dietary rules, eating chocolate and ice cream and taking lots of sugar in her tea, she is – most of the time – careful as far as her physical energy consumption is concerned and tries not to exert herself: "If I use up too much energy, I always pay for it later." (Downham 9)

Having suffered from leukaemia for a long time, Tessa seems to have adopted a set of strategies helpful in the painful moments of her last months: "I try to remember the rules about feeling sick – whenever possible get lots of fresh air, open a window or go outside if you can. Get good at distraction therapy – do something, anything, to keep your mind off it." (Downham 21)

One technique Tessa frequently makes use of is visualization. She mentally tries to step out of her body, to forget her existence as a human being and to take on a completely different identity: "I close my eyes and imagine I'm a tree drenched in sunlight, that I

have no desire beyond the rain. I think of silver water splashing my leaves, soaking my roots, travelling up my veins." (Downham 38)

She seems to get relief also from a rather contrary method: Instead of trying to forget about her existence and in this way also her pain, she at times very consciously faces her situation and focuses on the ache: "I sit forward and massage my scalp. I focus on the pain behind my eyes and try and make it go away." (Downham 243)

Additionally, Tessa at times also tries to distract herself from her pain by concentrating on particular things, often seemingly random: "As he packs sterile cotton into my nose, I try and concentrate on simple things – a chair, the twin silver birch trees in Adam's garden and the way their leaves shiver in sunlight." (Downham 222)

Finally, the girl silently talks to herself and encourages herself to keep going. She seems to make use of this technique especially frequently at later stages of her illness: "Keep breathing, just keep doing it. It's easy – in and out." (Downham 251)

Tessa does not have to cope with the pain accompanied by her illness on her own. The people in her environment seem to increasingly be able to see the signs and react accordingly, either asking her whether or how they can help her or simply taking a hand in what seems to have been done. Sometimes it is the mere presence of one or more members of her family that is able to relieve her suffering: "It's lovely listening to them talk, their words gliding into each other. My bones don't ache so much with the three of them so close." (Downham 80)

Particularly Tessa's father is always there and willing to do whatever he can to relieve his daughter's pain. While she is having her lumbar puncture, he takes her hand and encourages her to squeeze it and to "[g]ive [him] the pain." (Downham 36) When she expresses her fear of hurting him, he puts her mind at ease, explaining: "When your mother was in labour with you, she held my hand for fourteen hours and didn't dislocate any fingers. There's no way you're going to hurt me, Tess." (Downham 38)

It is her father who reads literature on organic nutrition, who serves his daughter lots of fruit and is convinced of the fact that "it's not the food in your life that brings health, but the life in your food that really counts." (Downham 190) He even wants to raise the

population's awareness by talking about "dietary needs" (Downham 187) and the fact that they are "not being subsidized" (Downham 187) on the radio.

In contrast to this, her mother offers her chocolate biscuits and, at least initially, generally does not seem to be able to support her daughter and give her the necessary assistance. The fact that Tessa is extremely sceptical as far as her mother's empathy is concerned becomes particularly obvious from Tessa's thoughts and doubts in a hospital scene when Tessa's mother is asked to distract her daughter: "I wish he hadn't said that. What's she going to do? Dance for us? Sing? Perhaps she'll do her famous disappearing act and walk out of the door." (Downham 223)

Apart from admitting that she is not at all informed about her daughter's course of disease and therefore cannot help the doctor, she comes up with a memory of their shared past. She astonishes Tessa by revealing a story that is able to create a positive atmosphere and at the same time proves that she is indeed capable of helping her daughter.

In addition to her father and her mother, also Adam is there for Tessa by day and night: He is able to relieve her by helping her in day-to-day business, by sleeping in her room in order to save her from the fear of loneliness and, above all, by showing her his love: "I've been in hospital all night, my head's stuffed with cotton. I'm clutching a paper bag full of antibiotics and painkillers, and my arm aches from two units of platelets delivered through my portacath. And yet, it's extraordinary how happy I feel." (Downham 227)

5. THE NEEDS OF THE DYING RELATED TO THE NOVEL'S PROTAGONIST

The first in David Kessler's list of "needs" of the dying, namely the need to be treated as a living human being, seems to be of particular importance for Tessa. Even though – or maybe exactly because of the fact that – Tessa is constantly reminded of her illness by the pain she suffers from, the tests she has to undergo and the drugs she is required to take, she feels alive and consciously decides not to stop living before her death: "All I know is that I have two choices – stay wrapped in blankets and get on with dying, or get the list back together and get on with living." (Downham 55) The fact that she talks about having choices implies that she is of the opinion that she is in control and that it is up to her to make something out of the last months, weeks and days of her life. At the same time, she signals the readiness to take the responsibility for the success or failure of her final moments.

She knows what she wants, tries very hard and is convinced of the fact that she has the right to get it. When – just to mention one striking example – her father expresses his doubts about the whole purpose of the plan that Adam moves in, she threatens her father by telling him that she is otherwise going to either move to Adam's house or to "bugger off to Scotland and live in a croft." (Downham 228)

Rather than generally struggling with her fate, she is often able to focus on the remaining positive sides and aspects and learns to savour them: "I know there's a particular curve (the only curve I have left) where my spine meets my bum, and that when I lean on one hip, that curve pushes itself towards Adam." (Downham 233)

She wants the people in her environment to realize that her life is not over until the very moment of her death and that she is full of plans, hoping to get the chance to execute them: "[I]t's not as if I'm going to drop dead this very second. I've got a whole list of things I'm going to do first." (Downham 85)

Luckily, Tessa is surrounded by people who understand and respect her need to actively participate in all decisions concerning her care. At different stages in the course of the young woman's disease, numerous decisions have to be made and she is not only always involved, but also the one who decides. Tessa feels that she has the right to do

so, arguing: “I want to die in my own way. It’s my illness, my death, my choice. This is what saying yes means.” (Downham 265)

The fact that her father seems to struggle accepting Tessa’s way of coping with the situation becomes apparent from the young girl’s suffering from the feeling that her father blames her for “not dying properly.” (Downham 44) Unhappily, she expresses her displeasure: “You’re always coming in my room telling me to get out of bed or pull myself together.” (Downham 44)

The two most consequential decisions she makes are to stop the heavy and tiring treatment with side-effects and to leave hospital and spend the last days of her life at home, surrounded by the people she loves and who love her. The girl’s need to die in peace and dignity is respected by the members of her family as well as the medical staff.

The knowledge that her life is about to end does not only result in her wanting to make the most out of her limited amount of time, but also in her dreading to sooner or later be forgotten. Tessa’s wish to be remembered becomes obvious several times in the novel. Fame is the sixth thing on her list. In response to her father’s question she explains what she actually means by this word:

> I mean Shakespeare. That silhouette of him with his perky beard, quill in hand, was on the front of all the copies of his plays at school. He invented tons of new words and everyone knows who he is after hundreds of years. […] Then there’s Marilyn. Elvis. Even modern icons like Madonna will be remembered. Take That are touring again and sold out in milliseconds. Their eyes are etched with age and Robbie isn’t even singing, but still people want a piece of them. Fame like that is what I mean. I’d like the whole world to stop what it’s doing and personally come and say goodbye to me when I die. What else is there? (Downham 185)

This seems rather exaggerated and immodest, of course, but Tessa also expresses this wish in a completely different and much more realistic manner: She tells her best friend that her explanation for not wanting to have sex with a “druggie” (Downham 12) or somebody “pissed” (Downham 12) is that she wants the guy not only to remember this special moment, but also – even more importantly – her.

David Kessler’s need of the terminally ill to maintain a sense of hopefulness can also be found in Tessa’s case. On the one hand, she does indeed have a strong feeling of hopefulness at certain stages in the development of her disease. When getting the in-

formation that she has only a few months left to live and coming to the conclusion that she wants to make the most out of this time, she is overwhelmed by this feeling: “It seems so clear to me. I feel almost hopeful, which is mad. I want to live before I die. It’s the only thing that makes sense.” (Downham 54)

On the other hand, however, Tessa reacts in a rather reluctant way as far as the hope of the people close to her is concerned. She feels that her father’s hope is inappropriate and merely a manifestation of his denial. Indeed, there seems to be a difference between Tessa’s hope and her father’s hope. After all, Tessa – in contrast to her father – seems to be able to feel hope without denying the inevitable.

Tessa is cared for by people who generally are compassionate, sensitive and knowledgeable. However, this does not save her from disappointment. In the course of time, she realizes that neither her father nor her mother are as strong as she had thought or hoped them to be and that the members of the medical staff are far from being able to answer all of the questions she desperately wants to know. Tessa says about her best friend: “I need her. Her energy. The fact that things always happen when she’s around.” (Downham 57)

In the course of time, it is not only the members of her family and her friends, but also the members of the medical staff who comfort her and try to be there for her as well as they can. Repeatedly, also Tessa finds herself in the position of the comforter, particularly for her father and – as in the following quote – her brother:

> “I’m going to be the only kid at school with a dead sister.”
> “It’ll be cool. You’ll get out of homework for ages, and all the girls will fancy you.”
> Cal thinks about this. “Will I still be a brother?”
> “Of course.”
> “But you won’t know about it.”
> “I bloody will.”
> “Are you going to haunt me?”
> “You want me to?”
> He smiles nervously. “I might get scared.”
> “I won’t then.” (Downham 286)

According to Kessler, it is necessary for the dying to express feelings and emotions about pain in their own way. Tessa talks about her feelings and emotions only rarely and with very few people. Her father complains about her never talking to him,

expressing his worries: “If you won’t talk about it, how can I help you?” (Downham 2) It is only when she is no longer able to do so that she feels the wish to talk to her father about her fears: “I want to tell Dad how frightened I am, but speaking is like climbing up from a vat of oil.” (Downham 254)

The one person Tessa is able to talk with about her feelings, particularly also her fears, already at a rather early stage, is Adam. Having lost his father and therefore knowing grief, Tessa feels that they share something. It seems to be the awareness of this special connection that makes her express her feelings and emotions in a way she does not normally do. At one point, she admits: “People think if you’re sick you become fearless and brave, but you don’t. Most of the time it’s like being stalked by a psycho, like I might get shot any second. But sometimes I forget for hours.” (Downham 116)

Tessa’s father is aware of the fact that it is important for his son to participate in the process of his sister’s death. He very consciously seems to try not to exclude him but to make him take part in his sister’s final moment of her life. He takes him to hospital, and at Tessa’s deathbed encourages him to say goodbye to his sister.

Tessa is afraid of loneliness both before and after death. She wants the members of her family to sit with her and expresses her gladness about the fact that “night porters and nurses and long-distance lorry drivers exist. It comforts me to know that in other countries with different time zones, women are washing clothes in rivers and children are filing to school.” (Downham 288) Similarly, she likes to find that Adam is “in the middle bit of sleep – a part of this world, but also part of another. This is strangely comforting to me.” (Downham 239)

Whereas she frequently and explicitly utters the wish not to be alone in the last weeks before her death and insists on Adam’s spending the nights with her, Tessa’s fear of loneliness after death only becomes obvious in one of her instructions for her father: “I want you to keep me at home until the funeral. Please can someone sit with me in case I get lonely?” (Downham 283)

It seems to be important for Tessa to know that the sanctity of her body will be respected after death. This becomes apparent in one of the letters Tessa writes to her father. She gives him instructions about her burial: “I want to be buried in my butterfly dress, my lilac bra and knicker set and my black zip boots […]. I also want to wear the

bracelet Adam gave me. Don't put make-up on me. It looks stupid on dead people." (Downham 283)

The people who care for Tessa are aware of Tessa's need and right to understand the process of death and that therefore all her questions have to be answered honestly and fully. She feels that due to the extraordinary situation she finds herself in some of the rules do not apply to her: "The nurses aren't allowed to use doctors' first names, and normally I'd never dare. But something's shifted. This is my death and there are things I need to know." (Downham 259)

She asks her medical doctor about how much time she has left and wants her nurse to tell her "how it will be," (Downham 280) expressing the wish to be informed not only about the further development of her medical state until her death, but also the pain she has to expect. The fact that Tessa is also interested in the happenings after her death becomes obvious in a conversation with her brother in which she asks him to tell her about the development of dead bodies. He agrees to "find out and let [her] know." (Downham 138)

Generally, her decision is respected and she is informed about her situation in an open and very honest way. At one point, her medical doctor tells her: "Your options are limited. We can keep going with blood and platelets if you want to, but it's likely their benefit will be short lived. If you became anaemic straight after a transfusion, we would have to stop." (Downham 259) Her expectations in this situation are not met: "I'd always thought that being told for definite would be like being punched in the stomach – painful, followed by a dull ache. But it doesn't feel dull at all. It's sharp. My heart's racing, adrenalin surges through me. I feel absolutely focused." (Downham 259)

Spirituality plays an ambivalent role in the last weeks and months of Tessa's life. On the one hand, she has an agnostic and nihilistic attitude. It becomes obvious in several passages of the novel that the girl cannot identify with the Christian faith, stating – in reply to her friend's suggestion to "try and believe in God" (Downham 4) – that she thinks "he might be dead." (Downham 5) In a conversation with her nurse about the existence of heaven, Tessa states that she thinks that it is "a great big lie. When you're dead, you're dead." (Downham 105)

Tessa “mostly believe[s] in chaos.” (Downham 174) She feels completely at the mercy of her fate and seems to try to flee the chaos with superstition: “If I can fit my name on this piece of paper over fifty times, everything will be all right.” (Downham 28) Whether or not Tessa actually believes in her spell does not seem to be of prior importance in this connection.

This also holds true for her idea to profit from her best friend’s health: “It crosses my mind that it might be possible to suck some of her good white cells into me […], but she pushes me off before I have a chance to test my theory.” (Downham 89) Tessa quite obviously does not believe in the feasibility of the fulfilment of her wish. What she seems to express by these thoughts is her desperation and at the same time possibly also envy of Zoey’s health.

Another manifestation of Tessa’s superstition is her looking for and seeing signs wherever she goes. She is of the opinion that “[t]here are signs everywhere. Some you make. Some come to you.” (Downham 247)

On the other hand, the young woman has a shallow belief in esoteric rebirth. She muses about taking on a different identity, returning to earth and meeting again the people she loves: “Maybe I’ll come back as somebody else. I’ll be the wild-haired girl Adam meets in his first week at university.” (Downham 321)

6. THE FIVE STAGES OF GRIEF RELATED TO THE NOVEL'S CHARACTERS

6.1. Tessa Scott

6.1.1. Stage 1 – Denial

The fact that Tessa denies the hopelessness of her situation for a long time and has come to realize reality only rather late becomes obvious from a statement made only several weeks before her death in which she admits: "I used to believe that Dad could do anything, save me from anything. But he can't, he's just a man." (Downham 173)

Tessa is stunned and cannot believe that it should be her who is affected by the rare terminal illness:

> this mad psycho tells everyone to get into a field and says I'm going to pick one of you just one of you out of all of you to die and everyone's looking around thinking it's so unlikely to be me because there's thousands of us so statistically it's completely unlikely and the psycho walks up and down looking at everyone and when he gets near me he hesitates and he smiles and the he points right at me and says you're the one and the shock that it's me and yet of course it's me why wouldn't it be I knew all along (Downham 298)

Kübler-Ross's finding that "denial" is not restricted to the beginning of the process of grieving, but comes up again occasionally at later stages when the patients have already – at least partially – accepted their illness can also be found in Tessa's process of grieving. After all, already in a very weak state of health at the end of her life she is still worrying about her diet: When her father tells her that she can have as much ice cream as she wants, she is of the opinion that "[h]e must've forgotten I'm not allowed sugar or dairy." (Downham 256) It is Kübler-Ross's term isolation that describes the phenomenon that Tessa shows signs like this of her maintenance of hope and at the same time frequently talks about the proximity of her death.

In the novel Jenny Downham also describes instances of daydreaming, which is also discussed by Kübler-Ross. In her conversation with her father Tessa speculates about her convalescence and talking about the future she would like to live to see:

> "You never know, maybe I won't die if I'm at home."
> "It'd be lovely if you didn't."
> "I'll do my A-levels instead. Then I'll go to university."
> […] "That's a good idea."
> "I'll get a job, and maybe one day I'll have children – Chester, Merlin and Daisy." (Downham 272)

Tessa adapts her behaviour to that of her interlocutors. Whereas she does not deny her terminal illness and expresses her fears when talking with Zoey and Adam from the beginning onwards, open and honest conversations with her father take place only at the very end. This is explained by Kübler-Ross by the fact that Tessa knows that both Zoey and Adam are able to cope with the tragic reality, whereas her father needs more time.

6.1.2. Stage 2 – Anger

Just as described by Kübler-Ross, Tessa does not see why it should be time for her to leave everything she loves behind: "It's not fair. I don't want to die like this, not before I've even lived properly." (Downham 54) She is angry because – except for her – everybody gets the chance to live on and this results in her egoistic wish that Adam might join her: "I wish it was possible to smear cancer cells onto his arse. I could reach from here, and he'd be mine for ever." (Downham 235)

Her anger is directed against both unknown people as well as individuals she loves – a fact that makes it very difficult to cope with for the members of the family. No matter how hard he tries, her father is not able to please her: "The boundaries change all the time. One minute she doesn't want anyone near her, then she wants to be held for hours. She won't leave the house for days, then disappears when I'm least expecting it." (Downham 146)

He addresses her anger, asking: "What happens if anger takes you over, Tessa? Who will you be then? What will be left of you?" (Downham 137) Tessa admits that "[m]aybe Dad's right and I'm turning to anger." (Downham 139) She fights her anger and tries to "focus on good things, but it's so hard to scramble out." (Downham 141) Tessa is both aware of her anger and of the consequences of her negative feelings: "A counsellor I saw at the hospital said it's not my fault. She reckoned there must be loads of sick people secretly wishing malevolence upon the healthy." (Downham 120)

However, Tessa is not only angry at the people in her environment, but also at her disease, which does not progress in the way it has been said it would: “This isn’t how it’s supposed to be. Not sudden, like being hit by a car. Not this strange heat, this feeling of massive bruising deep inside. Leukaemia is a progressive disease. I’m supposed to get weaker and weaker until I don’t care any more. But I still care. When am I going to stop caring?” (Downham 254)

Anger comes again and again, also when she gets the information that Adam will go to university and live his life without her. She tells her father: “I’m sick of being stuck in a bed day after day while the rest of you get on with your lives. I hate it! I hate all of you! Adam’s gone for a university interview, did you know that? He’s going to be here for years doing whatever he likes and I’m going to be under the ground in a couple of weeks!” (Downham 272)

6.1.3. Stage 3 – Bargaining

Jenny Downham also features the third and least well known stage of grief. Tessa hopes to be able to avoid death by acting in a certain way. She wishes to be in control of the situation and able to change it for the better, coming up with seemingly absurd ideas: “I need to keep away from the modern world and all its gadgets and then I won’t be sick.” (Downham 101) In a conversation with one of her medical doctors she tinkers with the idea of not listening to his words, thinking that she “then […] won’t know what he’s going to say, and maybe then it won’t be true.” (Downham 52)

The idea of being able to change her fate also comes to her mind on the playground with her brother, thinking that “[m]aybe if I swing high enough, the world will be different.” (Downham 59)

In this respect, also the compilation of her list seems to be of interest. After all she says: “I’m not going to die until all ten are done.” (Downham 12)

6.1.4. Stage 4 – Depression

Suffering from her current loss, her weakness causes the loss of her ability to function the way she did before. It is obvious that Tessa goes through a reactive depression. She often cannot be bothered to get up and is listlessly spending her time at home.

However, in Tessa's coping with her terminal illness, preparatory depression seems to be more prevalent. Just as Kübler-Ross describes, she is very much aware of the fact that she is going to lose everybody she has ever known and everything she has ever had within a short time.

She admits that she will miss a lot, arguing that "where I'm going, you can't take anything with you." (Downham 6) Realizing the severity of her situation, she suffers from her future loss: "I really won't ever go back to school. Not ever. I'll never be famous or leave anything worthwhile behind. I'll never go to college or have a job. I won't see my brother grow up. I won't travel, never earn money, never drive, never fall in love or leave home or get my own house." (Downham 54)

6.1.5. Stage 5 – Acceptance

She is aware of the fact that she has got nothing to lose and faces the tragic reality: "The world will roll on without me. I have no choice. I'm full of cancer. Riddled with it. And there's nothing to be done." (Downham 281) She savours precious moments and is aware of the fact that she needs them, "like talismans, to survive an impossible journey." (Downham 244)

She asks herself: "How did this happen so quickly? How did it really come true?" (Downham 296) These questions are manifestations of the doubts Tessa had for a long time and prove that she has – finally – realized that "it's happening now and it's really really true and however much they all promise to remember me it doesn't even matter if they do or not because I won't even know about it because I'll be gone." (Downham 253)

6.2. The people in Tessa Scott's environment

6.2.1. Stage 1 – Denial

Tessa is of the opinion that her father is not able to cope with the entire situation and believes that he denies its gravity: "I've been told there are five stages of grief, and if that's true, then he's stuck in stage one: denial." (Downham 42) The young woman remembers her father expressing his conviction that she "will get well again." (Down-

ham 47) In response to his daughter's expression of the fear that the results of her lumbar puncture will be bad, he says that "[t]hey won't be." (Downham 39)

Also Tessa's mother seems to be caught in the first stage of grief for a rather long period of time. She accuses her husband of making it generally sound worse than it is and tells her daughter to think positively: "You'll be fine, don't worry. I know you'll be fine." (Downham 32)

Even though Zoey seems to be resistant to denial and faces her best friend's tragic situation from the very beginning onwards, her disregard results in Tessa feeling that her fate might not be that tragic at all. Tessa informs the reader about the fact that "[b]eing with her is like being told they got it wrong and I'm not dying, someone else is, and it's all a mistake." (Downham 60)

6.2.2. Stage 2 – Anger

The second stage of grief becomes mostly evident in the behaviour of Tessa's father. After he had brought her back home from shoplifting, Tessa says that he "looks mad and breathless, as if he hasn't slept for weeks and is capable of anything." (Downham 135) The disease of his daughter wears him out both physically and emotionally and results in his being impatient and angry in situations he – under normal circumstances – would be able to handle without difficulties. This becomes obvious particularly in the contact with his son, when he shouts at him after having looked through Tessa's property and when he was disturbed by Cal:

> "Can't I have any peace?" […] "Not even for five minutes?"
> "Were you looking at Tessa's stuff?"
> "Is it any business of yours?"
> "It is if I tell her."
> "Oh for God's sake, give me a break!" (Downham 145)

6.2.3. Stage 3 – Bargaining

Kübler-Ross's third stage of grief is hardly represented at all in connection with the people in Tessa's environment. The reason for this seems to be the fact that the narrative situation of Downham's novel hardly provides the reader with insights into the individual character's minds.

One incident which seems to point towards bargaining is a situation in which Cal tries to take action in order to prevent his sister's death:

> Last night, when we were watching TV, he tied our legs together with a skipping rope. We looked as if we were entering a three-legged race.
> He said, "No one will take you if you're tied to me."
> "They might take you as well!"
> He shrugged, as if that didn't matter to him. "They won't get you in Sicily either; they won't know where you are." (Downham 242)

Also, sitting at her deathbed together with his father and Adam, Cal initially refuses to act on his father's advice by giving her his permission to go, fearing that this "might make her die." (Downham 324)

6.2.4. Stage 4 – Depression

Tessa remembers that, several weeks after the incident, she was "thinking how Dad couldn't possibly have understood, because he was crying too much to listen," (Downham 34) when being informed by one of her medical doctors about the severity of her situation. When Tessa tells her father that she is "sick of being stuck in a bed day after day," (Downham 272) "Dad starts to cry. He sinks onto the bed and puts his head in his hands and just weeps. I don't know what to do. Why is he weaker than me? I sit next to him and touch his knee." (Downham 272)

Also Cal repeatedly shows signs of going through Kübler-Ross's fourth stage of grief. At one point in the last days of her life, according to Tessa, "[h]e grins but almost immediately starts to cry, silently at first, and then great gulping sobs. As far as I know this is only the second time he's ever cried, so maybe he needs to." (Downham 287)

6.2.5. Stage 5 – Acceptance

The fact that Tessa's father has finally come to realize his daughter's state of health becomes obvious when he – knowing that she is on a diet – tells her that she can have "fifty ice creams if that's what [she wants]." (Downham 256) In the final moments of her life, he gives his daughter the permission to leave: "It's all right, Tessa, you can go. We love you. You can go now." (Downham 323)

Also her mother finally comes to accept Tessa's approaching death, telling her that she wishes she "could swap places" (Downham 310) with her daughter in order to be able to "save [her] from this." (Downham 310)

Both Tessa's brother and Zoey show signs of acceptance throughout the novel. Apart from his insensitive question whether he can "go on holiday" with his parents after his sister's death, Cal also tells her that he is going to miss her and finally takes his leave of Tessa with the words: "Bye, Tess. Haunt me if you like. I don't mind." (Downham 325) Not showing signs of the other four stages of grief, Zoey reminds her best friend that "time isn't on [her] side" (Downham 12) and that "[e]verybody dies." (Downham 68)

Also Adam seems to have accepted the gravity of his girlfriend's illness from the beginning onwards. He does not only try to spend as much time as possible with her, but also does his best in order to make the most out of each and every single encounter.

In the course of her disease, Tessa makes the observation that "[p]eople tend to get a bit freaked when they find out, like they just can't bear it." (Downham 85) She feels that Zoey reacted differently from most of the people who were informed about her disease, informing the reader about the fact that she "was the only girl at school who wasn't afraid of [her] illness." (Downham 60) In contrast to most of Tessa's friends, she does not prefer to keep a distance, nor is she afraid of getting too close to her.

Not only Tessa's acquaintance Jake and her friends and colleagues from school, but also the radio journalist and his assistant seem to feel uncomfortable as far as Tessa's disease is concerned. They are relieved when they find a possibility to change the topic. Fiona and Beth's way of coping with the situation is a typical example. They feel uncomfortable and helpless as soon as they run out of polite questions, and they do not know how to cope with Tessa's sarcasm. They are highly relieved about the recurrence of a conversation about "normal" subjects.

In addition to the members of her family mentioned above, there are only two exceptions to this typical reaction after the confrontation with Tessa's terminal illness. One of them is Shirley, the employee in the supermarket who talks to her after the girl's attempted theft. The information about Tessa's poor state of health does not scare her. She remains stern and professional and does what her job requires her to do without any obvious meanderings from the usual proceedings.

The other atypical reaction is Sally's, Adam's mother. Sally is rather introverted and shy and seems to be consumed with grief after her husband's death in a car accident. The proximity of Tessa's death does not seem to reach the world she had found herself in since the loss of her husband.

The members of the medical staff hide behind their professional façade. They quite obviously try to keep the tragedy of their young patient's fate at a distance and struggle hard to maintain some communication with Tessa. Their insecurity about where to draw the line between honesty and protection results in their frequently feeling uncomfortable in conversations with Tessa.

Philippa seems to be aware of the fact that – despite of the physical proximity – her job requires her to keep a certain emotional distance to the dying. This reaction does not seem to be alien to Tessa. After all, after having experienced friendship with a terminally ill girl, Tessa decides not to let other people hurt her again: "Dead. Just like that, without even telling me. I decided not to bother with anyone else." (Downham 52)

7. EFFECTS OF THE KNOWLEDGE THAT THE END IS NEAR

7.1. Time management

The first wish Tessa writes on the wall behind her bed is: "I want to feel the weight of a boy on top of me." (Downham 1) She does this probably not only due to the fact that "[t]here's a pen, but not paper." (Downham 1) The much more convincing reason for not hiding the list of her last wishes seems to be that she wants "something to happen" (Downham 5) and feels that this is only going to be if she lets the world – starting with her best friend Zoey – know about it.

Tessa has an urge to use the time remaining as well as possible, is hungry for life and suffers from the fact that her situation prevents her from making valuable experiences: "If my life was different, I'd be out with Zoey. We'd have chips. We'd be standing on some street corner, licking salty fingers, waiting for action." (Downham 174)

As far as her trying to make up for what she misses is concerned, she feels the necessity of her best friend's help: "Without her, I guess I'll just stand here on the step and watch the clouds gather and burst. Water will run in rivulets down the kitchen window and another day will begin to collapse around me. Is that living? Is it even anything?" (Downham 83) Zoey encourages her to continue the list of unfulfilled desires in situations in which Tessa is at the brink of cancelling it, telling her: "It was fun! Don't give up on it. You were doing something with your life at last." (Downham 34)

The list is not resistant to change and is a clear indicator of Tessa's priorities at certain points in her life. Getting her parents back together, for example, replaces going to Spain as number seven on her list: "I was going to travel the world, but I swapped it for getting Mum and Dad back together." (Downham 194)

Of interest are also Tessa's utterances concerning the things that she thinks she will miss: "I'm starting to think of things like carrots. And air. And ducks. And pear trees. Velvet and silk. Lakes. I'm going to miss ice. And the sofa. And the lounge. And the way Cal loves magic tricks. And white things – milk, snow, swans." (Downham 7)

Initially planning to have ten items on her list, she finds out bitterly that "[t]en isn't enough any more" (Downham 229) and that "there's so much more [she] could add." (Downham 234) In the course of time, however, as the following part of a conversation between Tessa and her father reveals, she comes to terms with her situation and is satisfied with what she has got:

> "I'll always be here for you, Tess. Whatever you do, whatever you still have left to do, whatever your stupid list makes you do. You need to know that."
> "There's hardly anything left." (Downham 240)

Her father initially tries to forbid her to keep the list. Also later he points out that he is not happy about it, but when he realizes the importance this list has for his daughter he starts to accept it and even to support her in keeping it. However, in spite of their very close and friendly relationship, Tessa feels that her father does not understand her in this respect, musing on "how many miles [they] miss each other by." (Downham 187)

She is aware of the fact that everybody else has "lots more tomorrows" (Downham 161) and notes "[h]ow easy it is for them to talk about the future." (Downham 197) She accepts bitterly that Adam "glows with the future. I can see it in his eyes. […] He'll go to so many places without me." (Downham 276)

7.2. Intensity of perception and thinking

With the disease progressing, Tessa is able to savour the little things increasingly. She cherishes the flowers in her room and the fact that she is allowed to have juice and ice cream and is delighted by everyday commodities: "It's the pleasure of revolving doors – going round twice to celebrate the genius of the person who invented them." (Downham 265) She learns to live by the moment, thinking, when lying in Adam's arms: "I'm alive, blessed to be with him on this earth, at this very moment." (Downham 213)

Lying in her bed in the first floor, she "can hear the fat spitting, the slosh of gravy in the pan." (Downham 2) However, she doubts the reliability of her perceptions, arguing that she is not sure whether she "should be able to hear that from all the way upstairs." (Downham 2) Her additional remark that "nothing surprises [her] any more" (Downham 2) seems to prove that she has finally given up on trying to understand her body and its functions.

Everything seems volatile to her and she feels that she is aware of things others are not, for example that death surrounds us all. And it tastes like metal between your teeth." (Downham 181) She wants to show her brother "the rats on the towpath, the leaves ripped screaming from trees, the way people avoid what's difficult […]." (Downham 67) She is of the opinion that "[w]e make patterns, we share moments" (Downham 266) and explains that she sometimes feels to be "the only one to see it." (Downham 266)

Tessa's particular fascination with environmental phenomena becomes obvious on several occasions. She loves to look closely at different elements of the biota, observing its development from birth to death and trying to find similarities with human life in general and with her own existence in particular.

She repeatedly thinks about the genesis, development and magnitude of the universe, revealing at the same time her knowledge and her fascination: "the big bang was the origin of the solar system and only then was the earth formed and only then could life appear and after all the rain and fire had gone fish came then insects amphibians dinosaurs mammals birds primates hominids and finally humans[.]" (Downham 320)

She muses about "how small humans are, how vulnerable compared to rock, stars" (Downham 253) and that "only the sun remains. And the earth." (Downham 37) These thoughts make her feel humble and "tiny." (Downham 108) She expresses her conviction of her own insignificance compared to the magnificence of the universe:

> "I'm me and you're you, and all of them out there are them. And we're all so different and equally unimportant." […] "I don't know my seven and eight times tables and I hate beetroot and celery. You don't like your acne or your legs, but in the great scheme of things, none of it matters." […] I'm driving now. It's my face in the car mirror, my smile, my bones they'll burn or bury. It'll be my death. Not Zoey's. Mine. And for once, it doesn't feel so bad. (Downham 155)

The fact that she is unique puts her mind at ease. At the same time she seems to point towards the fact that each and every individual takes him- or herself and the problems much too seriously. She comes to the conclusion that people in general have very "little […] to say," (Downham 108) that words do not "reach people" (Downham 26) and that "[m]aybe nothing does." (Downham 26)

Both life and death play a very important role in her thoughts. Apart from her longing for the feeling of being alive, she is interested in and fascinated by life and wants to preserve it. She shows her interest by repeatedly reading books on pregnancy. She does not want Zoey to abort her baby and suffers from not knowing how to bring the suffering of the mouse in the cockroach trap in the kitchen to an end.

Making up her mind about the nature of life, she is convinced of the fact that "life is made up of a series of moments, each one a journey to the end." (Downham 165) She tells her friend Zoey: "Every few years we disappear […]. All our cells are replaced by others." (Downham 163)

She seems to find consolation in the fact that no living being is able to escape death and that it is merely a matter of time when an individual's life ends: "I will die first, I know, but they'll all join me one by one." (Downham 97) This is shared by Zoey who argues that "[w]e're all in the same boat, you know. We're born, we eat, we shit, we die. That's it!" (Downham 164)

Death taking up an increasing part of her daily thoughts, she thinks of the dead animals that had been buried in their garden and reflects on her fate: "I feel as if everything is zeroing in, a strange hallucination that all my life has been about this moment. I was born and grew up in order to receive this news and be handed this medicine by this woman." (Downham 281)

She muses about eternity and "of how there are more dead than living, of how we're surrounded by ghosts." (Downham 37)

Tessa thinks about death in various ways. She is afflicted with the idea that the most striking characteristic of death is "emptiness": "[A]ll that is warm will go cold. My ears will fall off and my eyes will melt. My mouth will be clamped shut. My lips will turn to glue. [...] No taste or smell or touch or sound. Nothing to look at. Total emptiness for ever." (Downham 141)

Interestingly, she – at the same time – clings to a rather romantic picture of her death:

> Cal says that humans are made from the nuclear ash of dead stars. He says that when I die, I'll return to dust, glitter, rain. If that's true, I want to be buried right here under this tree. Its roots will reach into the soft mess of my body and suck me dry. I'll be reformed as apple blossom. I'll drift down in

> the spring like confetti and cling to my family's shoes. They'll carry me in their pockets, scatter the subtle silk of me across their pillows to help them sleep. […] In the summer they'll eat me. Adam will climb over the fence to steal me, maddened by my scent, by my roundness, the shine and health of me. (Downham 204)

She expresses her wish to remain in familiar spheres, being able to be near the people she loves and make them happy by some means or other.

7.3. Memory

Memory seems to play a very important role in the confrontation with death, not only for Tessa, but also for the people caring for her, particularly her father and her mother.

Tessa's father comes up with pictures of Tessa's childhood. He tells his daughter about her birth, the time when she was a baby and keeps telling her that she has always been and will always be loved and cared for by her parents: "You can laugh at me, but it's true. It gets easier as your children get older, but it never goes away. I worry about you all the time." (Downham 80)

Tessa's mother frequently tells her about the shared past: "I used to take you on the bus to meet Dad in his lunch break and you'd sit on my lap and stare at people. You had such an intense look about you. Everyone used to comment on it." (Downham 304) She very often tells her daughter about her memories concerning their family holiday in Spain. Interestingly, she frequently comes up with stories about her own past, particularly her childhood years, her first boyfriend and the time when she met Tessa's father.

In the confrontation with Tessa's illness and death, also Adam comes up with certain memories. He tells stories about the life and particularly the death of his father.

Tessa's own attitude towards her past and her memories seems to be rather ambivalent. On the one hand, she wants to forget and tries to unburden herself by eliminating all of the things reminding her of the past, thinking, when burning things that are particularly loaded with memories, these moments will be destroyed forever: "Four years of pathetic optimism burns well – look at it flare!" (Downham 47) Moreover, she does not want to acquire new things in order not to create additional sources of pain.

On the other hand, however, she stresses the importance of memory by claiming that she "need[s] more memories" (Downham 279) and freaks out when she suddenly cannot remember anything any more, giving her the feeling that due to this loss of her memories she "became no one." (Downham 77) However, she has the strong wish to be remembered.

Childhood plays a very important role in her memories. Apart from the fact that she – according to her own thoughts – has been ill for such a long time that she hardly can remember the time when she was healthy, Tessa frequently thinks about her own childhood and the time before her diagnosis: "My mum was in labour for fourteen hours with me. It was the hottest May on record. So hot, I didn't wear any clothes for the first two weeks of my life." (Downham 304)

Interestingly, the more her disease progresses, the more frequently she compares herself to a child. She comments on Adam holding her like a baby and her father feeding her like you would a baby.

She has memories of her time at school, and refers particularly often to the journey to the beach with her family. The hotel at the sea is full of memories for her. Of importance is the inside of the wardrobe door in the hotel room in which she and her mother had written their names. She is fascinated by the fact that she had been healthy at that time: "Not a single bit of me is the same as when I was last in this room. I was someone else when I wrote my name in there, someone healthy." (Downham 164)

Tessa muses about the best moments of her life: "I told her [Zoey] about the time I was practising handstands with my friend Lorraine. I was eight, the school fair was the next day, and Mum had promised to buy me a jewellery box. I lay on the grass holding Lorraine's hand, dizzy with happiness and absolutely certain that the world was good." (Downham 227) She informs the reader about the fact that this moment has been replaced by kissing Adam and making love with Adam.

The young girl repeatedly remembers her mother leaving her and the rest of the family: "I'm twelve. I get home from school and Mum's on the doorstep. She has her coat on and a suitcase at her feet. She gives me an envelope. 'Give this to your dad when he gets home.'" (Downham 305)

Tessa muses about the life threatening moments in her life, coming to the conclusion that she has actually "been dying all [her] life." (Downham 316) Towards the end, she has the feeling that it is "[l]ike charades, this going over of memories." (Downham 304) The memories in the last moments of her life seem to be of particular interest. Her weak state of health is the cause of her rather confused perception of reality: "I weep for a dog, hit by a car and buried. We never had a dog. This is not my memory." (Downham 305)

In the last seconds of her life, Tessa memorizes different moments of her life:

> Angel Delight on a beach.
> A fork whisking against a bowl.
> Seagulls. Waves. (Downham 323)
>
> […]
>
> There's sun in my teacup.
> Zoey stares out of the window and I drive out of town. The sky gets darker and darker. (Downham 325)
>
> […]
>
> Adam blows smoke at the town below. Says, "Anything could be happening down there, but up here you just wouldn't know it." (Downham 326)
>
> Adam strokes my head, my face, he kisses my tears.
> We are blessed. (Downham 326)
>
> […]
>
> The sound of a bird flying low across the garden. Then nothing. Nothing. A cloud passes. Nothing again. Light falls through the window, falls onto me into me. (Downham 327)

7.4. Challenging the borders

Tessa's awareness of her illness and of the recognition that it will terminate her life prematurely results in her feeling that she has the right to make the most out of it, notwithstanding certain moral rules. She is convinced of the fact that these rules do not apply to people in her situation any longer. She admits that she sometimes likes being ill because this gives her the feeling of being placed in a specific position and that she is therefore able to challenge any kind of norm or limitation. She recklessly tells people what she thinks and does not shake hands with people she does not like, pretending not to be able to move her arms.

It is Tessa's best friend, Zoey, who initially makes her aware of the fact that she does not have to worry about what her parents or other grown-ups tell her to do, arguing that "[t]here are no consequences for someone like you!" (Downham 10) Interestingly, it is also Zoey who points out a border with an unparalleled and potentially even offensive honesty: "You can't assume everyone's free just because you are." (Downham 151)

Generally, the people she gets in contact with and who know about her state of health treat her very understandingly. The members of her family, her friends and even the medical staff tolerate her bursts of anger, her – at times – sharp tongue and try to do their best in order to enable Tessa to live the final months and weeks of her life in a way that is as self-determined and free of constraints as possible.

However, this issue seems to be especially difficult to accept for her parents, particularly for her father. He has been responsible for her upbringing for her entire life and feels that he has to adapt the rules he has set to the new situation he and his family are confronted with. On the one hand, he wants her to be happy as much and as often as possible and, therefore, does not want to keep her from doing the things she wishes to do. On the other hand, he feels that there are certain borders and that Tessa's state cannot justify her misbehaviour in each and every situation.

Tessa's father brings this topic up and explains that there are certain borders that cannot be stretched, even when taking into consideration the situation she finds herself in, arguing that "[t]here are some things you're entitled to […]. There are some rules we can stretch for you, but there are some things that you can want all you like and you're still not having." (Downham 135)

As far as her "jester's licence" is concerned, Tessa's feelings seem to be rather ambivalent. On the one hand, she savours being "immune to the rules." (Downham 153) She does not feel the necessity to conform to the conventions and, for example, to hide her antipathy to certain people. It almost seems as if the fact that she has only a limited amount of life time left makes her expect the same respect that normally is granted to elderly people only. This becomes particularly obvious in her relationship with people of higher social status: She is daring enough to call her doctor by his first name.

On the other hand, however, Tessa is aware of the fact that she carries responsibility and that she cannot do whatever she feels like doing in each and every situation. This attitude becomes obvious after her shopping trip with Cal when she has a bad conscience for spending a large amount of money and apologizes for her behaviour: "I didn't think my card would actually do all that. In every shop I thought they'd refuse it, but they never did. I got receipts though, so we can take it all back." (Downham 77)

7.5. Characterization and (change in) character relationships

7.5.1. Tessa Scott

Tessa is sixteen years old and, having been diagnosed acute lymphoblastic leukaemia at an age of twelve, has lived with the knowledge of her disease, and that it is likely to be terminal, for a number of years. She enjoyed school education until the age of fourteen, English literature classes obviously having left their traces. After all, in her "Instructions for Dad" she informs him about the fact that she does not want him to "under any circumstances read that poem by Auden," (Downham 284) because this has, in her opinion, "been done to death (ha, ha) and it's too sad." (Downham 284) Instead, she wants "someone to read Sonnet 12 by Shakespeare." (Downham 284)

She is in some way a typical young woman and interested in shopping. Tessa spends a large amount of her father's money on clothes on her shopping spree with her brother. Her special interest, however, is in the secrets of nature, the mysteries of the universe and the principles of the origins, development and ultimate end of life.

Jenny Downham describes her protagonist as "selfish and inconsiderate, angry and afraid, but also capable of profound love, empathy and self-awareness."[41] Additionally, she claims that [h]er illness forces her to value things in a different way, to seek out the things that truly matter."[42]

Tessa is a fun-loving young girl who enjoys laughing and, in spite of her tragic situation, keeps her sense of humour. She finds Cal's present, the book *A Hundred Weird Ways to Meet your Maker*, "quite funny" (Downham 204) and frequently tries to lift the gloom in desperate situations and conversations. A typical example is the following part of a talk with one of her medical doctors:

> "Tessa, […] do you know what hypercalcaemia is?"
> "If I say no, can I have something else?" (Downham 76)

Her sense of humour becomes apparent also when she meets two former schoolmates and ends their unpleasant conversation with the words: "I have to collect the invites for my funeral." (Downham 129) "It's a shame I can't be there myself – I like parties. Text me if you think of any good hymns!" (Downham 129)

She has a strong will and learns to realize and achieve her goals in life. She does not want others to feel sorry for her and fears to be surrounded by people acting with false sympathy or wanting to profit from her situation: "I don't have any other friends – and before you suggest it, I don't want to make any. I'm not interested in rubberneckers wanting to get to know me so they'll get sympathy at my funeral." (Downham 44)

On the one hand, her illness makes her self-centred. She does not realize that her best friend is in a desperate situation herself and admits that she looks "at her properly for the first time" (Downham 124) only after a long period of time.

On the other hand, however, Tessa develops a high degree of responsibility for the people in her environment. She does not want the members of her family and her

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[41] Switzer, Kristen. "Author Profile: Jenny Downham." http://www.teenreads.com/authors/au-downham-jenny.asp (05/04/10).
[42] Switzer, Kristen. "Author Profile: Jenny Downham." http://www.teenreads.com/authors/au-downham-jenny.asp (05/04/10).

friends to worry too much about her and tries to alleviate their sadness after her death with instructions she writes for them.

Tessa's maturation results in her increasingly savouring the moment and becoming aware of the things that really count in her life, saying to herself: "And when [Zoey] has to go home, take a deep breath and tell her you love her. Because it's true. And when she leans over and whispers it back, hold onto her tight, because these are not words you would normally share." (Downham 293)

7.5.2. Relationships between Tessa Scott and the members of her family

7.5.2.1. Tessa Scott – Tessa Scott's father

The relationship between Tessa and her father is characterized not only by mutual respect and closeness, but also by love. Due to the fact that Tessa's mother left the family when her daughter was twelve years old, Tessa's father has become her main attachment figure.

Tessa's father is very protective and concerned and worries about both his children, but particularly Tessa, getting hurt physically or emotionally "all the time." (Downham 80) He goes through the entire medical process with her, tries not to let her know that she is at times an encumbrance for him and accuses people of insensitivity who do not treat his daughter in a particularly understanding way. He wants to protect her from pain, asking her to "give [him] the pain." (Downham 36) Being a very organized person, he develops a certain routine that enables him not only to care for his two children, do the housework and even to take the time to give his daughter driving lessons, but at the same time also to look for a cure.

He repeatedly states that she is always able to rely on him and that he feels the necessity for her to talk to him and that he wants to be included in her world of thoughts: "I'll always be here for you, Tess. Whatever you do, whatever you still have left to do, whatever your stupid list makes you do." (Downham 240)

Tessa is aware of the fact that her father is always there for her and is not only very thankful for what he is doing for her, but also for what he gave up for her: "For hours you sat in hospitals and never, not once, complained. You brushed my hair like a

mother should. You gave up work for me, friends for me, four years of your life for me. You never moaned. Hardly ever. […] I was outrageous. Wanting, wanting so much. And you never said, 'That's enough. Stop now.'" (Downham 307)

She relies completely on her father, seeing in him her last resort. The fact that Tessa – at least for a long period of time – has high hopes and deep trust concerning the possibilities and abilities of her father, which becomes particularly obvious in such statements as: "I used to believe that Dad could do anything, save me from anything. But he can't, he's just a man." (Downham 173)

At the same time, however, Tessa sometimes has the feeling that she is stronger than her father and wants him to "[s]top pretending [she's] going to be all right." (Downham 193)

Tessa likes to make him laugh and even though Tessa sometimes ignores his fear and acts irresponsibly, she generally does not want to scare her father or to make him worry too much about her. She wants to be hungry "[f]or him" (Downham 283) and does not "want to hurt [him]" (Downham 38) neither emotionally, nor physically. Even after death she does not want him to get in too much trouble because of her. She asks him to visit her grave, but not to force himself: "[D]on't kick yourself if you can't, or if you move house and it's suddenly too far away." (Downham 285)

Even though Tessa sometimes feels misunderstood by her father, their relationship is very good. Being rather patient, he tolerates Tessa's outbursts of fury and reacts with sadness and disappointment, but is never angry and only very rarely and in extreme situations becomes angry at her. However, he sometimes needs space and additionally is aware of his daughter's occasional misbehaviour and sometimes feels he has to excuse this.

Their relationship seems to become closer not only because of her illness, but also because of Tessa's father's acceptance of Tessa's relationship with Adam. Whereas they are initially not able to talk about their feelings, the following open and honest conversation takes place rather at the end of the young girl's life:

> He wipes his nose on his shirt sleeve and looks at me. He looks like Cal.
> "You've really had enough?"
> "I've really had enough."

> I put my arm round him and he leans his head on my shoulder. I stroke his hair. It's as if we're floating about on a boat. There's even a breeze from the open window. We sit for ages. (Downham 272)

Overwhelmed by her fear, Tessa is finally not able and willing any more to spare her father and wants to include him in her emotional world:

> I want to tell Dad how frightened I am, but speaking is like climbing up from a vat of oil. My words come from somewhere dark and slippery.
> "Don't let me fall."
> "I've got you."
> "I'm falling."
> "I'm here. I've got you." (Downham 254)

7.5.2.2. Tessa Scott – Tessa Scott's mother

As long as her mother had lived with them, Tessa was looking for her mother's attention and extremely happy whenever she got it. This becomes obvious in the memories that Tessa has about her mother, when they were hiding themselves from her father and her brother on their family holiday in Spain: "I was really excited. She'd left Cal with Dad. It was me she'd chosen." (Downham 163)

Tessa would like to have a much closer relationship to her mother than she has, a feeling that seems to have been even more prevalent when she was a little girl. Even though she did not seem to want to lose the contact to her husband and to her children, her mother is not used to spending time with her children. Tessa on one occasion states that "[g]etting involved in matters of discipline goes against all her [i.e. her mother's] principles." (Downham 144)

The two women do not openly show their love for each other or express it verbally.

Tessa's mother is an outgoing, easygoing person and sometimes seems to have childish character traits, which makes Tessa at times feel older than her own mother.

Although her mother appears to do her best, Tessa thinks that she fails in her role as a parent. After all, she is absolutely helpless and does not know what to do in situations in which Tessa would need a strong person at her side. Only in the course of time she is occasionally able to give Tessa the feeling of being safe and that "[s]he speaks [her] language at last." (Downham 222)

Tessa does not trust her and thinks that she might leave her and the rest of the family again. She does not forgive her mother, which becomes obvious on several occasions. She wants her father to tell her mother that she wants "presents – expensive juice, loads of magazines and new make-up. If she's going to be crap, she can at least buy me stuff." (Downham 256)

Tessa's mother loves her daughter and loves remembering their shared past. She describes her daughter as a "wonderfully imaginative little girl" (Downham 223) and as an "easy child." (Downham 223)

Her mother tells her about her first boyfriend and she quite obviously believes in romance and, thus, understands Tessa's feelings for Adam. However, she also becomes increasingly worried about her daughter, telling her that "[o]ther people can't always give you what you want." (Downham 232)

Their relationship seems to become better after their night together in the hospital, when Tessa feels safe in her mother's arms.

They neither talk about their feelings in general, nor about their feelings for each other in particular. It is only a few days before Tessa's death that her mother expresses her emotions verbally and tells Tessa that she would like to save her. When she finally tells her that she loves her, Tessa feels that it is "Like three drops of blood falling onto snow." (Downham 311)

Tessa does not trust her mother and thinks that she cannot be sure that her mother is there for her when she needs her. She constantly fears that she might leave her and the rest of the family again. In the course of time, however, the relationship between Tessa and her mother becomes deeper. Even though Tessa appears to be unable to forgive her for having left the family in the past, she increasingly tries to understand her mother's past behaviour and asks her for her reasons. Unfortunately, however, her questions remain unanswered.

Tessa likes the fact that her mother increasingly knows what to do and spends time with her. Despite their difficult relationship and the distrust Tessa has to her mother, Tessa does call for her in the last moments of her life. Ironically, the mother does not make it

to her daughter's deathbed before Tessa dies and, therefore, just like most of the time in her life, the mother is not there when her daughter needs her most.

7.5.2.3. Tessa Scott – Cal Scott

The relationship between Tessa and her brother is a very close one. They know each other very well, which becomes obvious in situations in which Tessa is not able to hide her feeling sick. They do not only joke a lot, but are also rude to each other. Even though they often quarrel, and their father has to intervene sometimes when he feels that his son does not act appropriately, they help each other and stand in for each other as soon as either their parents or others talk in a derogatory way about their sibling.

Tessa envies him for his looking "sane and healthy," (Downham 273) being impressed by "[w]onderful rage as Cal stomps to the door. […] His body able to yank the door open and slam it behind him." (Downham 298)

Their relationship is also characterized by honesty. They talk openly about death in general and about Tessa's physical decline in particular. She feels that "whatever he says will be right, like he's some grand magician touched by cosmic truth." (Downham 138)

Tessa's love for her brother becomes obvious in several situations. She does not want to scare him, but rather to protect him against other people scaring or hurting him. Additionally, she writes in her "instructions for Cal" (Downham 299): "Don't die young. […] Don't fight in any war, or join a cult, or get religion, or lose your heart to someone who doesn't deserve it." (Downham 299) Furthermore, she tells him: "Don't think you have to be good because you're the only one left. Be as bad as you like." (Downham 299)

Tessa loves her brother and Cal loves his sister as well. He sends her a present to the hospital and is frequently worried about her state of health – telling her that she is not supposed to eat certain food.

She has a high opinion of him, thinking that he understands love "[b]etter than most people." (Downham 308) In spite of the weakness resulting from her illness, she feels the responsibility of an older sister and gives him pieces of advice on how to cope with

the situation they find themselves in: “Throw the telly out of the window if you want, Cal. It made me feel better.” (Downham 286)

Their relationship seems to change over time. They increasingly express their feelings for each other, that they will miss each other and Tessa enjoys the moments of being close to him. She tries to “savour the moment. He doesn’t often volunteer to hold my hand.” (Downham 73) Whereas she is initially not able to tell her brother about her feelings for him, she finally manages to tell Cal that she loves him and is very happy about the fact that she decided and managed to do so: “It’s easy. Even though it makes him cry ten times harder, I’m really glad I dared.” (Downham 288)

Although they become increasingly closer, their conversations gradually become less light-hearted. Tessa notices that “[s]omething has shifted between us since the hospital. Our jokes aren’t as easy.” (Downham 286)

7.5.3. Relationships between Tessa Scott and her friends

7.5.3.1. Tessa Scott – Zoey Walker

Tessa and Zoey have known each other and been friends for years. Tessa loves the fact that Zoey always has a plan and that she always knows what to do in order to get what she wants. Even though Tessa feels dependent on Zoey and envies Zoey for her good looks and her health, Tessa is aware that because of her terminal illness she knows something that her best friend does not. Zoey’s superficiality has an influence on Tessa’s thoughts: The young woman encourages Tessa to continue doing the things she wants to do and not to listen to the people in Tessa’s environment who want to stop her from living in a self-determined way.

Their relationship changes when Jake steps into Zoey’s life. According to Tessa, her best friend undergoes a radical change: “Before, she’d have had an idea. But now, because of Scott, she’s lost her definition. It’s like their edges got blurred together.” (Downham 121) Tessa suddenly feels that her friend is no longer interested in spending time with her and does not “even bother to hide it.” (Downham 122) Similarly, Tessa’s sudden interest in Adam hurts Zoey’s feelings.

In addition to jealousy, their relationship is also strained by Zoey's accusing Tessa of always being tired and by the fact that she is of the opinion that her best friend utilizes her illness in order to blackmail the members of her family and her friends. However, the two girls are always able to settle their differences and forgive each other for their misbehaviour rather quickly. Tessa does not accept anyone else criticizing Zoey and stands up for her when her father expresses his contempt, arguing that this is "nothing to do with [him] – she's not [his] daughter." (Downham 184)

Even though their relationship is based on honesty from the very beginning onwards, Tessa is only able to talk openly about her feelings to Zoey gradually, telling her that she is happy to have her as a friend, but also of her regret to let her down: "I feel like I've let you down. I won't be able to babysit or anything." (Downham 291)

Tessa's feelings for Zoey become especially manifest when Tessa thinks of her best friend after having been drugged by Adam's psychedelic mushrooms: "For a minute I don't know who he's talking about; then I remember Zoey and my heart floods with warmth." (Downham 94)

7.5.3.2. Tessa Scott – Adam

The relationship between Tessa and Adam changes from a casual acquaintanceship to a deep friendship and finally into a relationship based on love. At different stages in their relationship, Tessa and Adam are afraid of deepening their relationship. Whereas it is Adam who initially is afraid of either hurting Tessa or himself and, therefore, wants to keep some distance between them, Tessa comes up with this fear at a later point in time. However, they are able to overcome these fears and to establish finally a love-relationship.

Both young people seem to be rather mature, and seriousness is a connecting element in their relationship. They are connected and understand each other due to the fact that also Adam experienced the inevitability of death when his father died in a car accident: "I understand now why Adam's different from Zoey, or any of the kids I knew at school. It's a wound that connects us." (Downham 116)

Tessa enjoys spending her time with Adam, who is able to make her forget her illness temporarily and who enables her to savour the last weeks of her life: "Day after day it

was as if someone had taken my life apart and polished every bit of it really carefully before putting it all back together." (Downham 230) She trusts him and is able to talk with Adam about her fears and expectations in an open and honest way: "I want you to be with me in the dark. To hold me. To keep loving me. To help me when I get scared. To come right to the edge and see what's there." (Downham 237)

Whereas Tessa initially does not want Adam to see her smeared in blood when suffering from a strong nosebleed, she in the end has to accept that she cannot spare him from unpleasant sights and she loves him for making her feel attractive: "He touches me as if I'm precious, as if he's stunned, as if my body amazes him, even now, when it's failing." (Downham 262)

Tessa desperately needs Adam to be physically there for her and is afraid that Adam might only be there out of pity: "It's so difficult to get what I want. I worry that people only give me things because they feel guilty. I want Adam to want to be here. How will I ever tell the difference?" (Downham 238) Repeatedly, she asks Adam "to be real" (Downham 260) and explains that she does not want "anyone being fake." (Downham 260) She encourages herself to talk about her feelings from him honestly after having realized what really counts for her in their relationship in particular and in life in general: "Tell him you want to be held and don't be afraid that he might not want to, because if he says he will, then he loves you and that's all that matters." (Downham 294)

It is very difficult for Tessa to accept that Adam is going to "live so many years without her". When first being informed about his plans to go to university, she is disappointed. However, she quickly manages to cope with this knowledge. What remains is her deep grief which can be claimed to be nourished by Adam's love: "I don't want to be dead. I haven't been loved this way for long enough." (Downham 303)

7.5.4. Relationships between Tessa Scott and the medical staff

Generally, Tessa is disappointed by the doctors she is confronted with in the course of her medical treatment: "I keep hoping that in some hospital somewhere in this country I'll bump into the perfect doctor, but none of them are ever right." (Downham 76)

She is convinced that doctors “expect you to be polite and grateful. It makes their job easier.” (Downham 258) Tessa, however, seems to be of the opinion that it is not the patients’ task to make it easier for their doctors but that the medical staff should do their best in order to ease the physical and emotional pain of the sick and the dying.

One of Tessa’s biggest wishes is that her doctors should accept that she is the one who is affected most by her illness, and that she therefore has the right not only to be informed about her state of health, possible treatment and, very importantly, about the time left for her. Moreover, she would like the medical staff to overcome the gap between doctors and patients, to face her directly and on equal levels and, ultimately, to treat her as a living human being.

The relationship with Dr Ryan is an unpleasant one for Tessa. This is due to the fact that he is demonstratively serious, keeps the professional distance and does not respond to any of Tessa’s jokes. Most importantly, however, Tessa does not feel treated like a human being, but rather as an “obedient horse” (Downham 38) that has to undergo treatment without opposition or expression of emotions. During the execution of the lumbar puncture, the doctor informs the student that he is “using a twenty-five-gauge needle” (Downham 36) and “a five-millilitre syringe” (Downham 36) and gives statistical details: “Approximately one in a thousand people who have this test suffer some minor nerve injury. There’s also a slight risk of infection, bleeding or damage to the cartilage.” (Downham 38)

He does not address her personally and does not even say good bye when leaving the room.

Initially, Dr James Wilson is insecure about how to communicate with Tessa about her poor state of health as well as her limited chances and considers it necessary to disclose that to her in the presence of Tessa’s father. However, Tessa quickly convinces him of the fact that the information mainly concerns her and that she has the need and right to know as soon as possible: “He sighs very deeply, as if he can’t believe he’s about to give in. “Yes, we found disease in your peripheral blood. I’m very sorry.” (Downham 259)

Finally, he does not only answer her questions in an honest and sensitive way and inform her about her chances, but also admits that he does not know how long her transfusions are going to last and how much time she has left.

When she expresses her wish to leave the hospital, he accepts her demand for self-determination without forgetting to point out the existence of a "fine line between the quality of the life [she has] left and the medical intervention necessary to maintain it." (Downham 264) He stresses that the judgement is up to her. Generally, he shows sympathy, expressing his sorrow repeatedly and trying to enable her to do what she wants to do.

Tessa's relationship to the nurses is a much better one, possibly due to their closeness. She is of the opinion that "[n]urses never tell you what they know. They're hired for their cheeriness and the thickness of their hair. They need to look alive and healthy, to give the patients something to aim for." (Downham 75)

Even though the relationship between Tessa and Philippa is based on honesty and trust from their first encounter onwards, it changes significantly over time. Initially, Tessa describes Philippa as "stout as a ship" (Downham 103) and does not like her for suggesting to "normalize [her] situation" (Downham 106) by making use of the support of the community team or by going back to school. Moreover, Tessa feels alienated by the fact that Philippa tells her that it might be "tough on [her] dad" (Downham 107) to care for her all the time. Towards the end, Tessa develops strong sympathies for her nurse and thinks that – in turn – she "might be her favourite patient." (Downham 246)

A problem she sees herself confronted with as far as the medical staff is concerned is the unequal distribution of personal information: "I see different people all the time and they never introduce themselves properly. They like knowing all about me though." (Downham 105) Tessa approaches this problem by asking Philippa whether she has got a boyfriend and about her belief in God, trying to accumulate as many private details about her nurse as possible.

There seems to be a difference in the development between their physical proximity on the one hand and their emotional proximity on the other hand. In contrast to Tessa's expectations, it is only at the very end that her nurse hugs her: "Fat, kind Philippa,

helping all the people between London and the south coast to die. She reaches down and hugs me. She's warm and sweaty and smells of lavender." (Downham 282)

Their emotional proximity, however, seems to develop differently. Whereas Tessa and her nurse generally enjoy talking a lot, Tessa says on one occasion that she does not want Philippa to force herself to visit her again in the end, feeling that Philippa is finally distancing herself from Tessa: "She has a strange look on her face – professional, distant. She's begun to retreat, I think. What else can she do? Her job is to administer to the dying, but if she gets too close, she might fall into the abyss." (Downham 280)

The fact that Tessa trusts her nurse becomes particularly obvious at the end of her life when she asks her questions about the development of her disease and her death and admits her fear of not being able to handle the upcoming pain. Philippa returns this honesty by telling her that she would be scared if she was in her situation.

7.5.5. Relationships between Tessa Scott and others

7.5.5.1. Tessa Scott – Jake

The relationship between Tessa and Jake is first and foremost based on sexual desire. Sex being the first thing on Tessa's list, it comes in handy that Jake is more than willing to grant her this wish.

Tessa is aware of the fact that Jake does not have any deeper feelings for her, asking herself whether he is "giving the thumbs-up" (Downham 20) to his friend behind her back when it becomes clear that she is willing to have sexual intercourse with him.

On the one hand, Tessa is the one who takes the initiative and is happy that she is physically attracted to Jake, thinking that "[i]t would be so much harder if he was ugly." (Downham 18) On the other hand, however, sex – particularly with somebody she is not in love with – is not what she has ultimately desired: "Maybe we don't have to have sex. Maybe we could just lie down and snuggle up, find sleep in each other's arms under the duvet. Maybe we'll fall in love. He'll hunt for a cure and I'll live for ever." (Downham 23)

Very obviously, Tessa wants to have sex with Jake because she feels that this is something she has to have experienced before her death. It seems equally clear, however, that she does not feel comfortable. Not only does the fact that she is of the opinion that "[i]t seems rude not to" (Downham 25) sleep with him indicate this. It also seems striking that during their sexual intercourse she makes use of a distraction technique she normally uses when in tremendous physical pain:

> I notice that his shoes are on their side by the door. The door isn't shut properly. There's a strange shadow on the ceiling in the far corner that looks like a face. I think of a fat man I once saw sweating as he jogged down our street. I think of an apple. I think that a safe place to be would be under the bed, or with my head on my mother's lap. (Downham 25)

Since she desperately wants to know what sex is like, "what all the fuss is about," (Downham 25) but is very insecure as she does not know what to do and how to behave, she decides to pretend to be someone else. Both the fact that she wants him to turn the lights off and that she finds it "a relief to be with someone who doesn't know [her] at all" (Downham 19) seem to be manifestations of her insecurity. Interestingly, she at one moment has the feeling that she wants "to give him something" (Downham 22) and finds it important to tell him that she has "never done this before." (Downham 23)

Afterwards, Jake has a bad conscience and he expresses his hopes that it was alright for her and that she is "not going to say [she] didn't want to." (Downham 26)

At their first and only encounter after their shared night, Tessa feels that Jake "looks different – sweaty and vaguely embarrassed." (Downham 64) She "can see the guilt and pity in his eyes," (Downham 65) realizes that Zoey must have told him about her disease and imagines that he must have "grabbed the joint and inhaled so deeply that he didn't have to think about it." (Downham 66) Zoey, however, reassures Tessa that "Jake didn't mind." (Downham 67)

Tessa and Jake both do not seem to be interested in any further encounters.

7.5.5.2. Tessa Scott – Fiona and Beth

The relationship between Tessa and Fiona and Beth, two girls Tessa had gone to school with before leaving in year ten, is very reserved. Tessa feels that her illness and all of its side effects resulted in her losing track of the world she would normally find herself in,

that Fiona and Beth therefore suddenly "come from another planet," (Downham 127) and that there is no common ground for them to walk on.

As the three girls do not know what to say and how to behave, their encounter in the supermarket is both awkward and embarrassing for all of them. On the one hand, Tessa is disappointed by the fact that their reaction to the information about her terminal illness does not differ from the reactions of all the other people she had seen before. On the other hand, however, she is also sorry for them and wants "to give them permission to leave." (Downham 127) Tessa seems to be aware that she is in a powerful position, controlling the entire situation when leaving the two girls baffled, stating that she has to leave "to collect the invites for [her] funeral." (Downham 129)

7.5.5.3. Tessa Scott – Shirley

Shirley, a staff member of the local supermarket who deals with Tessa after her attempted burglary, is very reserved. She does what her job requires her to do and does not seem to easily become distracted from her tasks. Shirley reacts differently than the majority of the other people in Tessa's environment, leaving the girl astonished about the fact that "the c-word doesn't scare her" (Downham 132) and that "she calls [her] dad anyway." (Downham 132)

7.5.5.4. Tessa Scott – Sally

The relationship between Tessa and Adam's mother is a rather difficult one. It is based both on jealousy and on mutual understanding for the situations they find themselves in.

The two things these two women have in common are their love and dependence on and for Adam as well as their deep grief for the bereavement of a beloved person. Sally has to cope with the loss of her husband and of the life she had with him, Tessa with her illness and the knowledge that the time remaining for her in this life is limited.

At least initially, Tessa and Sally seem to find themselves in a competition for Adam's attention. When Tessa tells her that she lives next door and "came to see Adam," (Downham 112) according to Tessa "the sadness in her [i.e. Sally's] eyes deepens" (Downham 112) and she says that "that's what [she] thought." (Downham 112)

Also Tessa is jealous and envies Adam's mother for the time Adam spends with her: "I hate his mother, the lines on her forehead and round her eyes. I hate her wounded look. She lost her husband, but she didn't lose anything else." (Downham 235)

Interestingly, Tessa watches Sally's behaviour very carefully. From the following quote – Cal is showing a magic trick at the Christmas celebrations – it becomes obvious that Tessa is aware of the fact that drugs can influence a person's perception to a high degree and, rather than judging her, sees this as an explanation for an otherwise incomprehensible reaction: "Perhaps Sally's medication allows her to touch alternative realities, because it's really obvious how Cal's making the napkin move, but she looks at him in awe." (Downham 198)

In the course of time the relationship between the two women changes. It is rather towards the end that Tessa develops positive emotions for Sally and, ultimately, feels "a surge of love for her." (Downham 267) This might be interpreted as a proof of Tessa's growth of cognition. She no longer believes to be the only person in grief, realizing that also other people in her environment find themselves in difficult situations and need compassion and patience.

7.5.5.5. Tessa Scott – Richard Green

With Richard Green's character, a journalist making a live interview with Tessa and her father about her childhood leukaemia and the way they cope with her illness, Jenny Downham seems to draw the picture of all those people who want to take advantage of the terminally ill. Tessa thinks that Richard Green is neither interested in her as an individual, nor in her fate, but exclusively in his own benefits by publishing the interview. She is aware that as a journalist he "knows a good story" (Downham 191) and that he does the interview only for this reason. Tessa does not like him for treating her like a poor and desperate young woman and for ridiculing her wish to become famous: "He makes me sound like one of those sad little girls who put an advert in the local paper because they want to be a bridesmaid at someone's wedding, but don't know any brides. He makes me sound like a right twat." (Downham 191)

7.5.6. Relationships between the people in Tessa Scott's environment

7.5.6.1. Tessa Scott's father – Tessa Scott's mother

Tessa's parents have different social backgrounds: He comes from the working class and she from a middle class family. They have also very different ways of approaching things. Whereas he is sensible, considerate and could definitely be called a family man, the mother seems to be lightheaded, irresponsible and looking for adventures in life rather than caring for the family.

Already before their separation, it was Tessa's father who seems to have been responsible for at least part of the domestic chores, for Tessa remembers that – at least on holidays – he was the one who made the sandwiches and who would "mix it [Angel Delight] with milk on the beach in a Tupperware dish." (Downham 159)

Even though both seem to enjoy spending their time together, Tessa's father hopes for her to come back for good, quite obviously being dependent on her carefree and optimistic attitude towards life.

Tessa has mixed feelings about her parents' spending more and more time together because of her and obviously getting along very well. On the one hand, it is one of her wishes that they should be reconciled and reunited. On the other hand, it hurts her emotionally when she sees her parents together: "I stare at them. My mother. My father. His face is in shadow, the edges of her hair are tipped with light. I keep really still. Cal, next to me, keeps really still too. […] It hurts more than I could ever have imagined." (Downham 173)

7.5.6.2. Tessa Scott's father – Cal Scott

Tessa's father is very caring and worrying, but also strict and has clear rules, procedures and principles and expects his children to stick to them. Faced with the daughter's or sister's terminal illness, their relationship becomes closer. Not only does his father repeatedly show Cal that he loves him. He also tries to make him accept Tessa's illness and her approaching death in a sensitive way.

However, Cal at times suffers from his father's impatience, which results from the combination of stress and grief. The reader is informed about one outburst of anger with Cal who tells his sister about his father's words after Cal had caught him looking through Tessa's stuff in her room: "I hate him. He just called me a bugger and then he said the f-word." (Downham 145)

Generally, Cal's father encourages his son to be considerate and to spend as much time with his sister as possible. The way he involves his son in Tessa's death becomes obvious in his encouraging him to give her the permission to die, trying at the same time to diminish his son's fears:

> "Maybe you should say goodbye, Cal."
> "No."
> "It might be important."
> "It might make her die."
> "Nothing you say can make her die. She wants to know you love her."
> (Downham 324)

7.5.6.3. Tessa Scott's mother – Cal Scott

Tessa's disease and the knowledge of the proximity of her death also affect the relationship between her brother and mother. In contrast to Tessa, Cal is apparently not angry at his mother for having left the family. He enjoys the time with her. Their relationship gets closer, which becomes obvious in the course of her family's visit in hospital, when Tessa is moved and at the same time surprised that her brother wants to sit on their mother's lap: "I don't think I've ever seen him do this. I'm not sure Dad has either. Even Cal seems surprised." (Downham 79)

She pays attention to him and, interestingly, seems to understand his needs better than his father: Cal asks his parents whether they can go on a holiday after Tessa's death, his father looks "vicious and surprised at the same time" (Downham 149) and tells him that "[t]hat's a terrible thing to say!" (Downham 149) In contrast to this, his mother shows empathy, saying: "Tessa's been sick for a long time, hasn't she? You must feel really left out sometimes." (Downham 149)

7.5.6.4. Tessa Scott's family – Zoey Walker

Tessa's father appreciates Zoey's spending her time with his daughter and is grateful that she tries to cheer her up and, most importantly, for not quitting her friendship with Tessa. Her parents not being there for Zoey most of the time, he partly seems to take over the role of a father for the young woman. This becomes particularly obvious when he approaches Zoey in a very sensitive way and offers to talk to her about her unwanted pregnancy.

Zoey makes fun of Tessa's father's fear for his daughter and encourages Tessa to disobey some of his orders, even though she knows about his worries.

Even though Tessa's mother seems to like her daughter's best friend as well and tries to comfort her whenever necessary, the relationship seems to be more distanced, which can probably be accounted for by the lack of regular contact.

The relationship between Cal and Zoey is a rather tense one. When spending their time with Tessa, neither Cal, nor Zoey like to have the other person present or to take part in their conversations.

7.5.6.5. Tessa Scott's family – Adam

Initially, the relationship between Tessa's father and Adam is characterized by the former's scepticism as far as the sincerity of Adam's feelings is concerned. He fears that he might disappoint his daughter and let her down and, therefore, does not want him to move in. However, realizing the wholeheartedness of his daughter's feelings for the young man on the one hand and Adam's sense of responsibility on the other hand, he changes his mind and welcomes him in his house. In the course of time, he is grateful to Adam "[f]or not backing off," (Downham 316) arguing that, according to him, "[m]ost lads would've run a mile by now." (Downham 316)

Unlike her husband, Tessa's mother seems to trust Adam from the very beginning onwards and is impressed by the way Adam cares for her daughter. Also the relationship between Tessa's brother and Adam is a very good one, Cal adores him as if he was his brother. Whether Adam spends time with Cal out of real interest in the boy or in order to impress Tessa remains unclear: "Adam stays with Cal. He tells him that

rooks are very sociable, that this rook will have many friends, and they'll be grateful to Cal for burying it with so much care. I think he's trying to impress me." (Downham 140)

7.5.6.6. Zoey Walker – Adam

Zoey is jealous of Adam and does not trust him. She tries to talk Tessa out of spending her time with him and when being asked by her best friend why she does not like Adam and is "being so horrible" (Downham 87), Zoey answers: "Because he's boring and ugly and you've got me, so I don't know why you're even interested." (Downham 87)

She wants to be the one who does the things of the list together with Tessa and tries hard to convince her best friend that Adam is not needed. She frequently does this by striking out that Tessa and Zoey have known each other for years and have gone through numerous adventures together, whereas Adam has got to know her only very recently. She also does not try to hide her feelings in front of Adam and consciously gives him the feeling of not belonging to them, emphasizing that he does not know Tessa the way she does.

In the course of time, however, Zoey seems to realize that Adam's presence is good for Tessa and starts accepting him.

7.5.6.7. Zoey Walker – Zoey Walker's parents

Zoey neither has a good relationship to her father, nor to her mother. When noticing that she is pregnant, one of her biggest anxieties is that her parents will find out. They do not stand by her nor support her in her decision about whether to have the baby or not and generally do not give her the feeling of being loved and cared for. The reader is not informed about whether or not Tessa's terminal illness affects the relationship between Zoey and her parents in any way.

7.5.6.8. Adam – Sally

Adam cares for his mother and wants her to be happy. She is dependent on him and always tries to give her son the feeling that she loves him and that she cannot live without him. One example of this is when she asks her son "[w]hy he'd left her when

the world was ending" (Downham 185) after the fireworks of New Year's Eve celebrations.

Whereas Adam initially has a bad conscience when he is with Tessa and leaves his mother alone, he starts to realize that Tessa needs his comfort and presence more than his mother does. Sally comes to realize that Adam has his own life and that it is important to let her son go and to start taking her own life into her hands again. In the course of time, she accepts that her son loves Tessa and, therefore, wants to spend most of his time with her and that – in the long run – he will move from town and go to university in Nottingham.

7.5.6.9. Scott Redmond – Zoey Walker

The relationship between Scott and Zoey initially seems for both to be based exclusively on sexual interests. However, this changes and Tessa is deeply impressed by the influence Scott has on Zoey's behaviour and attitude: "Zoey used to live her life as if the human race was about to become extinct, like nothing really mattered. But around Scott, she goes all soft and warm." (Downham 89)

Tessa observes, not without envy, after not having seen her best friend for a while: "They came to visit me at the hospital, sat together on one chair like they got married and I missed it." (Downham 83)

When informed about the fact that Zoey expects a baby, Scott wants her to have an abortion and is willing to pay for it. After her initial disappointment about Scott's reaction and her wish never to have met him and to have an abortion, she – clearly influenced by Tessa's terminal illness – decides to have the baby despite the fact that Scott is not interested in the baby and leaves her.

CONCLUSION

In her novel for young adults, Jenny Downham pictures the way in which physical as well as emotional pain is dealt with by a dying young woman. Moreover, she describes how the members of the family, her friends, the members of the medical staff and other people she encounters cope with the knowledge of the protagonist's terminal illness.

In the course of the physical deterioration of her condition, Tessa Scott displays most of the typical Needs of the Dying as outlined by David Kessler. Her wish to be treated as a living human being and to be informed about her illness is particularly persistent. After all, this enables her to actively participate in the decisions concerning her care. Of equal importance for the young woman is the freedom to express her feelings and emotions the way she wants to as well as the wish to be surrounded by understanding and loving people.

In Tessa's process of grieving, all of Elisabeth Kübler-Ross's five stages can be found. Not only her thoughts and her words, but also her behaviour is in accordance with the stages of denial, anger, bargaining, depression and acceptance. Though these stages need not follow each other in a linear succession, they are evident particularly in the final months of her life. Jenny Downham thus renders a realistic picture of the process of coping with death.

In contrast to this, the individual stages of coping are not clearly manifest in the people Tessa is in contact with. This seems to be primarily due to the novel's narrative technique: Jenny Downham employs a first-person narrator-protagonist in which the reflector-character's story is narrated from an internal perspective. Thus, the reader is predominantly granted insights into the protagonist's thoughts and feelings. The only way in which the reader gets reliable insights into the thoughts and feelings of other characters is when the mode of presentation switches to dialogue. In *Before I Die*, Jenny Downham uses dramatic presentation very often and extensively.

The author describes a number of strategies the young woman comes up with in order to be able to endure the painful treatment of leukaemia. Moreover, the disease's treatment and its development are depicted in some detail including even medical terms.

Jenny Downham outlines several effects the knowledge of the protagonist's terminal illness has on her life as well as on the lives of people who are in contact with her. The probably most striking effect is the young woman's decision to compile a list of things she wants to do in the last weeks and months of her life. This list is a manifestation of her wish to make the most of her remaining lifetime and reflects her priorities in life.

The protagonist perceives environmental phenomena with increasing attention and awareness and she ponders on life and death frequently.

Facing death, the past is of importance not only for the protagonist, but also for the members of her family. They frequently come up with memories of their own childhoods and of certain shared events in the protagonist's childhood.

The awareness of her approaching death does not only change the protagonist's life, but also the lives of the people close to her. Her parents have to reconsider the rules they have set. They do not wish to keep their daughter from living her final weeks and months exactly in the way she wishes to, but they are also afraid that she might do harm to either herself or her environment. Thus the protagonist's parents find themselves locked in a conflict. Tessa's striving for freedom makes it necessary for her father and her mother to find suitable answers to the inevitable question of limits and borders.

Last but not least, significant changes can also be seen in the relationships between the different characters. Whereas the relationships between Tessa and the members of her family and her best friends, as well as the relationships between these people, are characterized by conscious interaction and loving behaviour, Tessa is also confronted with people who keep her at a distance. When talking to her, some people avoid the topic of her illness and her impending death. In several cases they even try to break the tie completely.

In *Before I Die*, Jenny Downham shows that in the face of a young life's end, serious changes in the life and in the way of living of both the terminally ill and the people in his or her environment are a direct and inevitable consequence and that the knowledge that death is approaching requires each and every individual concerned to make use of certain strategies in order to be able to cope with untimely loss of a beloved person.

Abstract

The paper at hand deals with Jenny Downham's novel *Before I Die*, which was published in the United Kingdom in 2007. Exhausting the potential of an interdisciplinary approach, a theoretical background both in the field of medicine and in the field of psychology is presented. In a textual analysis the representation of the protagonist's illness as well as the way in which the individual characters cope with the knowledge of the young woman's approaching death is investigated.

The medical part provides the reader with information about the typical symptoms, development and treatment of leukaemia. The psychological part informs the reader about the results of Elisabeth Kübler-Ross's and David Kessler's research in the field of death and dying. Whereas Kübler-Ross identified five stages that people who are confronted with either their own deaths or with the death of a beloved person go through, Kessler did research on the needs of the dying.

Based on this theoretical background, Jenny Downham's novel is being approached. A close reading is incorporated in order to analyse the representation of the protagonist's illness as well as the coping strategies of the young woman herself and the members of her family, her friends and the medical staff. Whereas physical pain only affects the protagonist herself, more or less all characters have to find means to deal with emotional pain. As a result, it is worth analysing the representation of Kübler-Ross's five stages of grief in relation to the characters portrayed by Jenny Downham. An analysis of the representation of Kessler's needs of the dying gives detailed insights into the final weeks and months of the protagonist's life.

The paper at hand also aims at depicting the effects of the knowledge of the protagonist's approaching death on the young woman's life as well as on the members of her family, her friends and the medical staff. The narrative situation of the novel enables Jenny Downham to effortlessly disclose the thoughts and feelings of the protagonist. Facing her own death, the protagonist gains maturity, thinks about using her time as good as possible and experiences emotions and events in a particularly conscious way. Additionally, it is memory that plays an important role both in the coping of the protagonist as well as of the people who care for her. The knowledge of the protagonist's approaching death does not only affect the relationships between the

protagonist herself and the members of her family, her friends and the medical staff, but also the relationships between these people. Finally, these changes are analysed.

Zusammenfassung

Die vorliegende Arbeit nähert sich in einem interdisziplinären Zugang dem im Jahre 2007 erschienen Jugendroman *Before I Die* der britischen Autorin Jenny Downham. Ausgehend von einem theoretischen Hintergrund aus den Bereichen der Medizin und der Psychologie erfolgt mittels „close reading" eine Textanalyse des Werkes im Hinblick auf die Repräsentation von Krankheit und der durch die vom bevorstehenden Tod der Protagonistin und Ich-Erzählerin betroffenen Personen entwickelten Strategien.

Der medizinisch-theoretische Teil konzentriert sich auf die typischen Symptome, den Krankheitsverlauf und die Behandlung von Leukämie. Der psychologisch-theoretische Teil widmet sich einer Einführung in das Werk der beiden Mediziner Elisabeth Kübler-Ross und David Kessler. In ihrer langjährigen und engagierten Tätigkeit im Umgang mit Sterbenden und deren Angehörigen beobachtete Elisabeth Kübler-Ross, dass gewisse Parallelen in der Bewältigung ihrer Trauer festzustellen sind. Die von Kübler-Ross definierten fünf Phasen lassen sich sowohl bei den Betroffenen, als auch bei deren Angehörigen beobachten. Von ebenso großer Bedeutung sind die Forschungsergebnisse des Amerikaners David Kessler, der sich intensiv mit den Bedürfnissen todkranker Menschen beschäftigt.

Ganz abgesehen von den körperlichen Schmerzen, die mit ihrer Erkrankung verbunden sind, schildert Jenny Downham vor allem auch den seelischen Schmerz, mit dem ihre Protagonistin und deren gesamtes Umfeld fertig werden müssen. Mit dem geschilderten theoretischen Hintergrund versucht die vorliegende Arbeit mittels Textanalyse der Darstellung der Krankheit und deren Auswirkungen auf den Grund zu gehen. Von zentraler Bedeutung wird dabei die Frage gesehen, in welcher Art und Weise sich die von Kessler erforschten Bedürfnisse todkranker Menschen und die von Kübler-Ross definierten Phasen der Trauerbewältigung im Roman finden lassen.

Schließlich wird untersucht, welche Auswirkungen die Kenntnis um den bevorstehenden Tod sowohl auf die Protagonistin selbst, als auch auf ihr unmittelbares Umfeld hat, wobei diesbezüglich ein besonderes Augenmerk auf die Mitglieder ihrer Familie, ihre Freunde und das sie betreuende medizinische Personal gelegt wird.

Ein wichtiges Anliegen ist es, neben den Veränderungen in der Gedankenwelt der Ich-Erzählerin, auch deren Wunsch, die ihr verbleibende Zeit möglichst gut zu verbringen, eingehend darzustellen. Abschließend wird der von Jenny Downham geschilderte, sich im Wandel befindliche Umgang der einzelnen Charaktere miteinander in dieser Arbeit ermittelt.

Bibliography

Primary Literature

Downham, Jenny . *Before I Die.* London: Definitions, 2008.

Secondary Literature

Cleton, F. J. (ed.). *Advances in acute leukaemia.* Amsterdam (et. al.): North-Holland Publ. (et. al.), 1974.

Kessler, David. *The Needs of the Dying: A Guide For Bringing Hope, Comfort, and Love to Life's Final Chapter.* New York: HarperCollins Publishers, 2007.

Kübler-Ross, Elisabeth. *Interviews mit Sterbenden.* Stuttgart: Kreuz-Verlag, 1992.

Kübler-Ross, Elisabeth. Kessler, David. *Life Lessons: Two Experts on Death and Dying Teach Us About the Mysteries of Life and Living.* New York: Simon & Schuster, 2002.

Kübler-Ross, Elisabeth. Kessler, David. *On Grief and Grieving: Finding the Meaning of Grief Through the Five Stages of Loss.* 2005. New York: Simon & Schuster, 2007.

Kübler-Ross, Elisabeth. *Kinder und Tod.* Gütersloh: Bertelsmann Club (et. al.), 1988.

Kübler-Ross, Elisabeth. *On Death and Dying.* London: Tavistock Publications, 1973.

Kübler-Ross, Elisabeth. *The Wheel of Life: A Memoir of Living and Dying.* New York: Simon & Schuster, 1998.

Kübler-Ross, Elisabeth. *Working It Through. An Elisabeth Kübler-Ross Workshop on Life, Death and Transition.* New York: Simon & Schuster, 1997.

Lilleyman, John S. *Childhood leukaemia: The facts.* Oxford: Oxford Univ. Press, 2000.

Lindorfer, Claudia Helene. “Doomed to Failure? The Search for Meaning in Life in the Face of Suffering, Death and Grief: An Interdisciplinary Approach to John Banville’s Novel *The Sea*.” Diplomarbeit. University of Vienna, 2008.

Lundy, Karen Saucier. Janes, Sharyn. *Community Health Nursing: Caring for the Public’s Health.* London (et. al.): Jones & Bartlett Publishers, 2009.

Prince, Gerald. *A Dictionary of Narratology.* Rev. ed. Lincoln, Nebraska: University of Nebraska Press, 2003.

Prince, Gerald. *Narratology: The Form and Functioning of Narrative.* Berlin: Mouton, 1982.

Reismüller, Bettina. “Long-term outcome of relapsed childhood acute lymphoblastic leukemia: A population-based analysis of the Austrian Berlin-Frankfurt-Münster (BFM) Group.” Dissertation. Medical University of Vienna, 2006.

Rosinska, Zofia. “Philosophical Psychology of Memory.” *Memory Work: The Theory and Practice of Memory.* Eds. Andreas Kitzmann, Conny Mithander and John Sundholm. Frankfurt am Main (et. al.): Lang, 2005, 25–43.

Silverman, Phyllis Rolfe. *Never Too Young to Know: Death in Children’s Lives.* New York (et. al.): Oxford University Press, 2000.

Small, Neil. “Theories of Grief: A Critical Review.” *Grief, Mourning and Death Ritual.* Eds. Jenny Hockey, Jeanne Katz and Neil Small. Philadelphia: Open University Press, 2001, 19–48.

Stanzel, Franz Karl. *A Theory of Narrative.* Cambridge (et. al.): Cambridge University Press, 1987.

“Teenage Novels.” *The Oxford Companion to Children's Literature.* Oxford (et. al.): Oxford University Press, 1984.

“YA Books In The UK.” *The Continuum Encyclopedia of Young Adult Literature.* New York (et. al.): Continuum, 2005.

“YA Literature.” *The Continuum Encyclopedia of Young Adult Literature.* New York (et. al.): Continuum, 2005.

"Young Adult Fiction." *The Cambridge Guide to Children's Books in English.* Cambridge (et. al.): Cambridge University Press, 2001.

"Young Adult Literature." *The Oxford Encyclopedia of Children's Literature.* New York (et. al.): Oxford University Press, 2006.

Electronic Sources

American Cancer Society. "How is childhood leukemia diagnosed?" American Cancer Society. 2010. <http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_How_is_childhood_leukemia_diagnosed_24.asp> (May 14, 2010).

Bardola, Nicola. "Was sich ein Teenager vor seinem Tod wünscht." Welt Online. 18 July 2008. <http://www.welt.de/kultur/article2226547/Was_sich_ein_Teenager_vor_seinem_Tod_wuenscht.html> (February 24, 2010).

BookBrowse.com. "Before I Die: Summary." BookBrowse. 18 May 2009. <http://www.bookbrowse.com/reviews/index.cfm/book_number/2031/Before-I-Die> (August 9, 2010).

BookBrowse.com. "Jenny Downham: Biography." BookBrowse. 18 May 2009. <http://www.bookbrowse.com/biographies/index.cfm/author_number/1486/Jenny-Downham> (May 1, 2010).

Children with Leukaemia. "Incidence of childhood leukaemia." Children with Leukaemia. 2010. <http://www.leukaemia.org/about-leukaemia/incidence-of-childhood-leukaemia> (April 28, 2010).

Children with Leukaemia. "Treatments." Children with Leukaemia. 2010. <http://www.leukaemia.org/about-leukaemia/treatments> (April 28, 2010).

Children with Leukaemia. "What causes leukaemia?" Children with Leukaemia. 2010. <http://www.leukaemia.org/about-leukaemia/what-causes-leukaemia> (April 28, 2010).

Children with Leukaemia. "What is leukaemia." Children with Leukaemia. 2010. <http://www.leukaemia.org/about-leukaemia/what-is-leukaemia> (April 28, 2010).

Collins, Robert. “Dying for a happier ending.” The Observer. 15 July 2007. <http://www.guardian.co.uk/books/2007/jul/15/booksforchildrenandteenagers.features2> (August 9, 2010).

EKR Family Limited Partnership. “Biography.” EKR Foundation. 2010. <http://www.ekrfoundation.org/bio> (May 16, 2010).

Friedman, Russell. James, John W. “The Myth of the Stages of Dying, Death and Grief.” Sceptic. 2008. <http://grief-recovery.net/Articles/Myth%20of%20Stages.pdf> (April 26, 2010).

Hibbert, Katherine. “No trace of corn.” Times Online. 10 June 2007. <http://entertainment.timesonline.co.uk/tol/arts_and_entertainment/books/article1894252.ece> (February 18, 2010).

Kessler, David. “The Needs of the Dying.” Geriatric Times. 2001. Continuing Medical Education. 2005. <http://www.cmellc.com/geriatrictimes/g010540.html> (May 19, 2010).

Macmillan Cancer Support. “Causes and risk factors.” Macmillan Cancer Support. 2010. <http://www.macmillan.org.uk/Cancerinformation/Causesriskfactors/Causesriskfactors.aspx> (April 22, 2010).

Macmillan Cancer Support. “If someone else has cancer.” Macmillan Cancer Support. 2010. <http://www.macmillan.org.uk/Cancerinformation/Ifsomeoneelsehascancer/Ifsomeoneelsehascancer.aspx> (April 22, 2010).

Macmillan Cancer Support. “Living with and after cancer.” Macmillan Cancer Support. 2010. <http://www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Livingwithandaftercancer.aspx> (April 22, 2010).

Meet the Author Ltd. “Jenny Downham.” Meet the Author UK. 2010. <http://www.meettheauthor.co.uk/bookbites/1689.html> (February 18, 2010).

Online Computer Library Center. “Downham, Jenny.” WorldCat Identities. 2010. <http://worldcat.org/identities/lccn-n2007-39040> (February 17, 2010).

Satake, Noriko. Yoon, Janet M. “Acute Lymphoblastic Leukemia.” eMedicine. 6 April 2010. <http://emedicine.medscape.com/article/990113-overview> (March 12, 2010).

Schwartz, John Burnham. “What She Wants.” New York Times. 14 October 2007. <http://www.nytimes.com/2007/10/14/books/review/Schwartz2-t.html> (August 6, 2010).

Seiter, Karen. “Acute Lymphoblastic Leukemia.” eMedicine. 10 March 2010. <http://emedicine.medscape.com/article/207631-overview> (March 12, 2010).

Seiter, Karen. “Acute Lymphoblastic Leukemia: Follow-up.” eMedicine. 10 March 2010. <http://emedicine.medscape.com/article/207631-followup> (March 12, 2010).

Switzer, Kristen. “Author Profile: Jenny Downham.” Teenreeds.com. September 2007. <http://www.teenreads.com/authors/au-downham-jenny.asp> (May 4, 2010).

---. “Elisabeth Kübler-Ross.” Wikipedia. The free Encyclopedia. 1 October 2010. <http://en.wikipedia.org/wiki/Elisabeth_K%C3%BCbler-Ross> (May 16, 2010).

---. “Jenny Downham.” Wikipedia. Die freie Enzyklopädie. 7 November 2010. <http://de.wikipedia.org/wiki/Jenny_Downham> (February 17, 2010).

---. “Jenny Downham.” Wikipedia. The free Encyclopedia. 31 October 2010. <http://en.wikipedia.org/wiki/Jenny_Downham> (February 17, 2010).

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Curriculum Vitae

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